

**Exploration of the lived experience of Post-Traumatic Stress Disorder following a  
medical event.**

**A thesis submitted in partial fulfilment of the requirements for the Doctorate in  
Clinical Psychology**

**University of Sheffield**

**17/11/2013**

**Elizabeth Roberts**



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### **Structure**

This thesis was prepared using the following guidance:

Literature review: British Journal of Clinical Psychology

Research report: British Journal of Clinical Psychology

### **Word Counts**

Literature review (excluding references and appendices)	7877
Research report (excluding references and appendices)	11608
Appendices (excluding approval letters)	7561
References (literature review and research report)	2948
Total word count excluding references and appendices	19485
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Thanks Team Roberts!

### **Abstract**

This thesis is concerned with the lived experience of Post-Traumatic Stress Disorder (PTSD) following a medical event. It is comprised of a literature review and an empirical study. The literature review uses a meta-ethnographic methodology to synthesise data from qualitative literature and literature with a qualitative element that explores the lived experience of PTSD following childbirth. The results illustrate that difficulties trusting services, problems maintaining social relationships, and difficulties managing challenging emotions were common when participants developed PTSD following traumatic birth. The review demonstrated that women reported intrusive and worrying thoughts regarding their future as well as the event. These experiences may indicate health anxiety alongside PTSD following traumatic medical events. The review indicates that further qualitative exploration is needed into PTSD following different health conditions. It also demonstrates that further research is needed into the phenomenology of intrusive thoughts following medical trauma to explore whether these are indicative of PTSD or health anxiety.

The empirical study is an Interpretative Phenomenological Analysis of stroke survivors' experience of PTSD. The findings illustrate that there is a complex range of psychosocial difficulties associated with PTSD following stroke. Findings closely mirrored those from previous qualitative research into the lived experience of PTSD following medical events. Results were considered in relation to cognitive models of PTSD, but consideration was also given to grief models to help explain findings. Study limitations, future research, and clinical implications were discussed.

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## **Section 1**

### **Literature Review**

#### **Post-Traumatic Stress Disorder following childbirth: A meta-ethnography of women's experiences**



### **Abstract**

**Aim.** To conduct a meta-ethnography into the lived experience of Post-Traumatic Stress Disorder (PTSD) following childbirth.

**Method.** A literature search was undertaken, covering literature written after 1994 when the diagnostic criteria of PTSD were updated. Studies were screened and selected in-line with defined criteria. Quality appraisal was conducted using an adapted tool. The studies were synthesised using a meta-ethnographic approach.

**Results.** Seven papers were included. The papers fell into two groups: 1) factors contributing to the development of PTSD; 2) and the lived experience of PTSD. The groups were synthesised separately, then brought together in a final synthesis. This revealed that the experience of living with PTSD following childbirth impacts on a broad range of psychosocial domains, including pervasive difficulties with trusting others and a shift in participants' world-view. The review also found that some participants reported 'flashforwards' (anxieties surrounding future events) alongside flashbacks. Flashforwards may indicate co-morbid health anxiety as well as PTSD.

**Conclusion.** The review indicates that PTSD following childbirth leaves sufferers feeling psychologically and socially disabled. There are multiple clinical implications, including the need to assess whether intrusive thoughts are associated with the traumatic medical event or future concerns. This is necessary to ensure appropriate interventions.

**Key words:** Meta-ethnography, PTSD, traumatic birth, childbirth

## Introduction

Post-Traumatic Stress Disorder (PTSD) is an anxiety condition which is characterised by three main symptoms; re-experiencing (intrusive images, flashbacks, and nightmares), avoidance, and hyper-arousal. The Diagnostic and Statistical Manual of Mental Disorders-IV (DSM-IV; 1994) outlines PTSD as:

*‘...the development of characteristic symptoms following exposure to an extreme traumatic stressor involving direct personal experience of an event that involves actual or threatened death or serious injury or other threat to one’s physical integrity.’* (American Psychiatric Association, 1994, p. 424).

For PTSD to be diagnosed symptoms need to persist for a month or more following the traumatic event and to negatively impact on the individual’s social and occupational functioning (DSM-IV; American Psychiatric Association, 1994).

As traumatic birth can be accompanied by fear, helplessness and terror, and the belief that the mother or their baby may die, it can be defined as a ‘traumatic event’ (Anderson & McGuiness, 2008; Olde, van der Hart, Kleber, & Van Son, 2006). Studies suggest that 1% to 6% of women develop PTSD following childbirth (Creedy, Shochet, & Horsfall, 2000; Olde et al., 2006). Studies demonstrate that women (and their families) can experience multiple bio-psychosocial difficulties following traumatic birth including; ongoing physical pain, psychological distress, negative impacts on intimate relationships, and social isolation, alongside the PTSD symptoms of hyper-arousal, re-experiencing, and avoidance (Czarnocka & Slade, 2000). Moyzakis (2004) reported that women who experienced a traumatic birth often felt they had not had the opportunity to discuss the distress caused by their experiences. This led them to believe that their concerns would be dismissed by professionals, which caused women not to trust professionals, and not to seek support

in the longer-term (Moyzakis, 2004). Literature demonstrates that similarities and differences exist between PTSD following birth trauma and other traumatic events. Similarities include sufferers experiencing difficulties maintaining relationships due to their PTSD symptoms (Beck, 2011). Differences include lower prevalence rates of PTSD following birth trauma (Olde et al., 2006). Despite the growing evidence that PTSD can develop following traumatic birth, Mundy and Baum (2004) questioned whether it was actually PTSD that developed following medical traumas such as childbirth. They found that although people experienced PTSD-type symptoms following medical trauma, the intrusive thoughts and images that some people reported were more accurately described as ‘flashforwards’ rather than ‘flashbacks’. This is because the reported images and invasive thoughts were associated with anticipated futures as opposed to the initial medical trauma. Mundy and Baum suggested that the trauma of a life-threatening illness led to Generalised Anxiety Disorder (GAD) as opposed to PTSD. However, the DSM-IV (American Psychiatric Association, 1994) stipulates that the anxiety experienced in GAD is wide-ranging, as opposed to specific. The flashforwards that Mundy and Baum described focused on anxieties that participants experienced regarding their future health, which may be more accurately described as health anxiety (Salkovskis, Rimes, Warwick, & Clark, 2002). It is important to distinguish between the conditions, as Cognitive Behavioural Therapy (CBT) for GAD and health anxiety targets the process of the worry, rather than the content of particular anxieties (Barsky & Ahern, 2004; Wilkinson, Meares, & Freeston, 2011). However, CBT for PTSD involves a structured revisiting of clients’ experiences so that traumatic memories can be processed (Yehuda, 2002).

Though feminist writers do not recognise childbirth as a ‘medical event’ (Marsh, 1996; Moyzakis, 2004), most traumatic births involve medical intervention (Czarnocka & Slade, 2000). Consequently it is possible to argue that ‘traumatic’ births have shifted into the medical domain. As such it is important to consider Mundy and Baum’s (2004) proposition that an alternative anxiety condition (as opposed to PTSD) develops following traumatic birth. This conceptualisation will be considered throughout the review.

### **Aim**

The main aim of the review is to derive new conceptual understanding of the lived experience of PTSD following traumatic birth by drawing studies together in a way that is meaningful to theory.

### **Method**

This review had three stages; (1) a systematic search; (2) a critical appraisal; (3) data synthesis following Noblit and Hare’s (1988) and Malpass et al.’s (2009) principles of meta-ethnography.

### **Systematic search**

The Cochrane library was searched to establish whether an equivalent review had recently been undertaken. Two recent reviews were found into women’s experience of traumatic birth (Beck, 2011; Elmir, Schmied, Wilkes, & Jackson, 2010). On closer inspection, Elmir et al.’s (2010) paper examined birth trauma as opposed to PTSD following birth. The Beck (2011) paper examined PTSD following birth; however, it only analysed Beck’s papers. Subsequently it was decided to continue with the review. Shaw’s (2010) Context, How, Issues, Population (CHIP) Tool (Table 1) was used to identify the parameters of the review. This helped identify appropriate search terms.

Table 1

*CHIP Tool*

Study components	Description
Context	PTSD following a medical event
How	Qualitative methods or mixed methods with a significant qualitative element
Issues	Impact of living with PTSD following a medical event Biological aspects: physical changes since medical event Psychosocial aspects: including experiences of support, and shifts in emotional experiences
Population	Adult survivors of a medical event with resultant PTSD

**Search terms.** Search terms (see Table 2) were devised using Medical Subject Heading terms alongside keywords obtained from the literature (Beck, 2011; Elmir et al., 2010; Olde et al., 2006).

Table 2

*Search terms*

Trauma searches	Birth search terms	Phenomenology searches
Trauma*	Birth*	Qualitative*
Post-Traumatic Stress Disorder	Child-birth	Qualitative research
Post Traumatic Stress Disorder	Childbirth	Phenomenology*
PTSD	Birth trauma*	Phenomenological
Post-Traumatic Stress Symptoms		IPA
Post Traumatic Stress Symptoms		Interpretative*
		Analysis
		Discourse analysis

**Electronic databases.** The Web of Knowledge (WoK), PubMed, PsycInfo and Google Scholar were searched between April-June 2012. The search was date limited to 1994-present, as the definition of PTSD was updated in the DSM-IV (American Psychiatric Association, 1994). The researcher also conducted a manual search of the references of all relevant literature. A later search was conducted in October 2013 to establish whether any recent research had been published and to ‘catch’ any studies missed during the initial search. No further studies were found.

**Inclusion and exclusion criteria.** Papers were included if they; examined PTSD following traumatic birth, were conducted after 1994, used a qualitative methodology, were published in English, were undertaken with adult participants (over 18-years), and were published in peer reviewed journals. Papers were excluded if there was no reference to how PTSD was measured, or the research focused on one aspect of living with PTSD following traumatic birth.

**Search strategies and screening.** The reviewer combined the terms for PTSD, childbirth, and phenomenology in each of the databases. The Boolean terms of AND and OR were used to combine search terms, for example; *PTSD AND birth\* AND phenomenology*. The majority of returns were quantitative, and were therefore excluded. The remaining papers (n=10) underwent a second screening following the inclusion and exclusion criteria. Discussions took place with an independent researcher to decide whether to include four studies. Two on traumatic birth (Moyzakis, 2004; Thompson & Downe, 2008) were excluded because, although women self-reported a traumatic birth, there was no reference to them being screened or diagnosed with PTSD. It is important to recognise that experiencing childbirth as traumatic and developing PTSD following this are different phenomena. A third paper was excluded as, although it examined PTSD following childbirth, it specifically examined the impact this had on breastfeeding (Beck & Watson, 2008). A fourth paper explored women's experiences around their child's birthdays, i.e., the anniversary of their traumatic birth (Beck, 2006). This was included as although the emphasis was on the birthday, it also explored the wider lived experience of PTSD following birth. Further discussions took place with the research supervisor regarding two papers (Beck, 2004a; Beck, 2004b) which had a substantial overlap of participants (38 participants participated in each study). It was decided to use both studies as they focused on different experiences. The author (Beck) was then contacted

via email to confirm whether these papers were distinct studies, or whether data from the same study had been analysed with different foci. Beck responded, stating that though there was a substantial overlap of participants, that they were independent studies: Beck (2004a) focused on the women's experiences of professional care at the time of birth, Beck (2004b) focused on the lived experience of PTSD following birth. This resulted in the inclusion of seven papers. For a summary of the selection process see Figure 1.

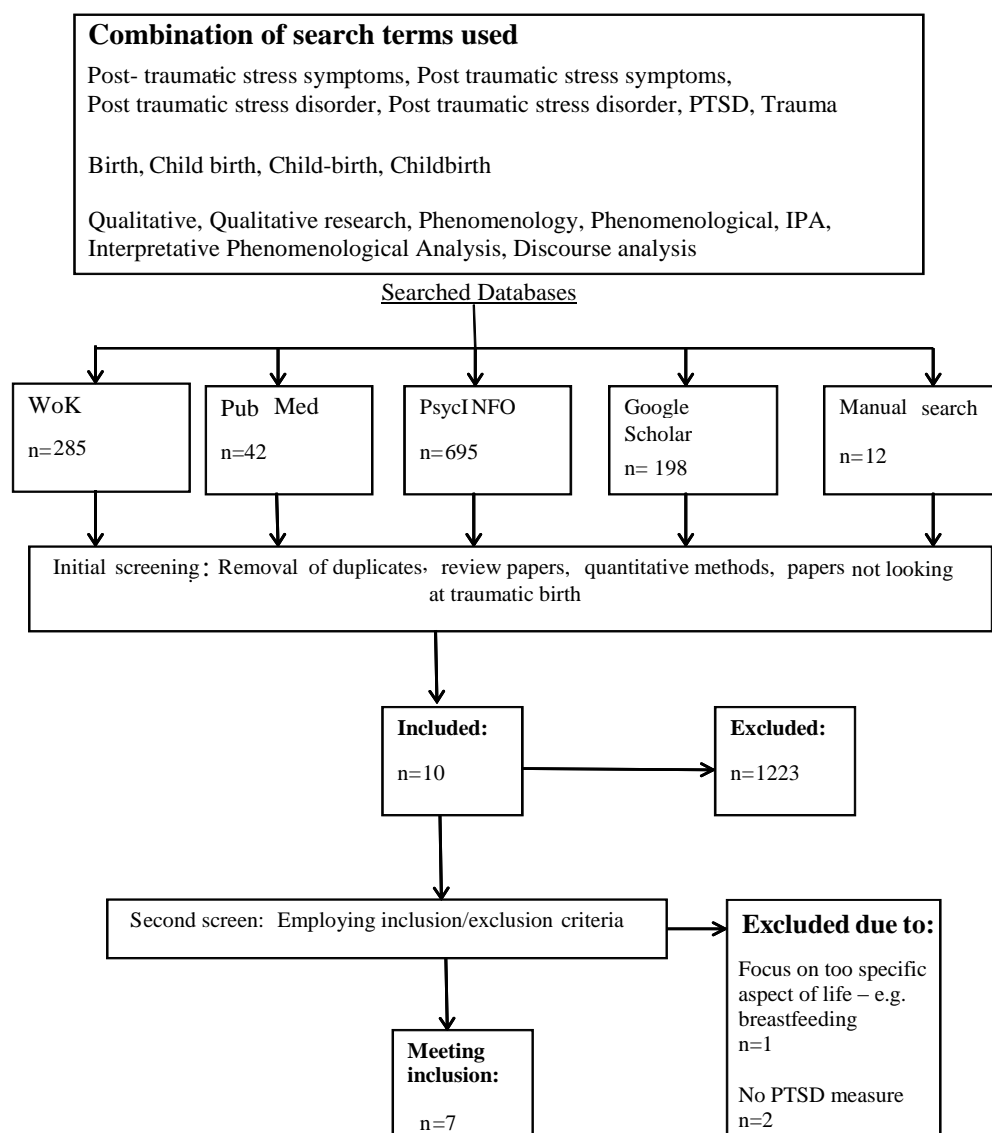


Figure 1. Selection procedure flow chart

## Quality appraisal

Appraising qualitative research is a contentious issue (Spencer, Ritchie, Lewis, & Dillon, 2003) and there is not a single set of standards for doing so (Atkins et al., 2008). Nonetheless, it was important to assess the quality of literature included in this review, in particular to judge whether appropriate methods were used to obtain the findings. It should be noted that quality appraisal was not used to exclude papers, but to assess the contribution they made to the review, as papers deemed 'poor quality' may still offer interesting contributions to reviews (Malpass et al., 2009).

Study quality was assessed using a tool specifically developed to assess qualitative research (Walsh & Downe, 2006). The tool examined the following aspects of each study; scope and purpose, design, sampling strategy, analysis, interpretation, reflexivity, ethical dimensions, and their relevance and transferability (see Appendix 1). The researcher undertook the quality assessment of all studies (see Appendix 2). The researcher's supervisor independently checked the appraisal of two studies. Once assessed, the researcher rated studies as either; key papers (KP) where studies were rich and could potentially make important contributions to the synthesis (n=1); satisfactory papers (SAT), where studies were of a solid standard and offered clear contributions (n=4); or unsure, when the paper's relevance or value to the synthesis was not clear (n=2) (Malpass et al., 2009). Following assessment and categorisation, three studies, (Allen, 1998; Ayers, 2007; Beck, 2006) were appraised by an independent researcher. Any differences of opinion were discussed and agreement was reached regarding appraisals and categorisations made. Figure 2 provides a flow chart of the quality assessment process.



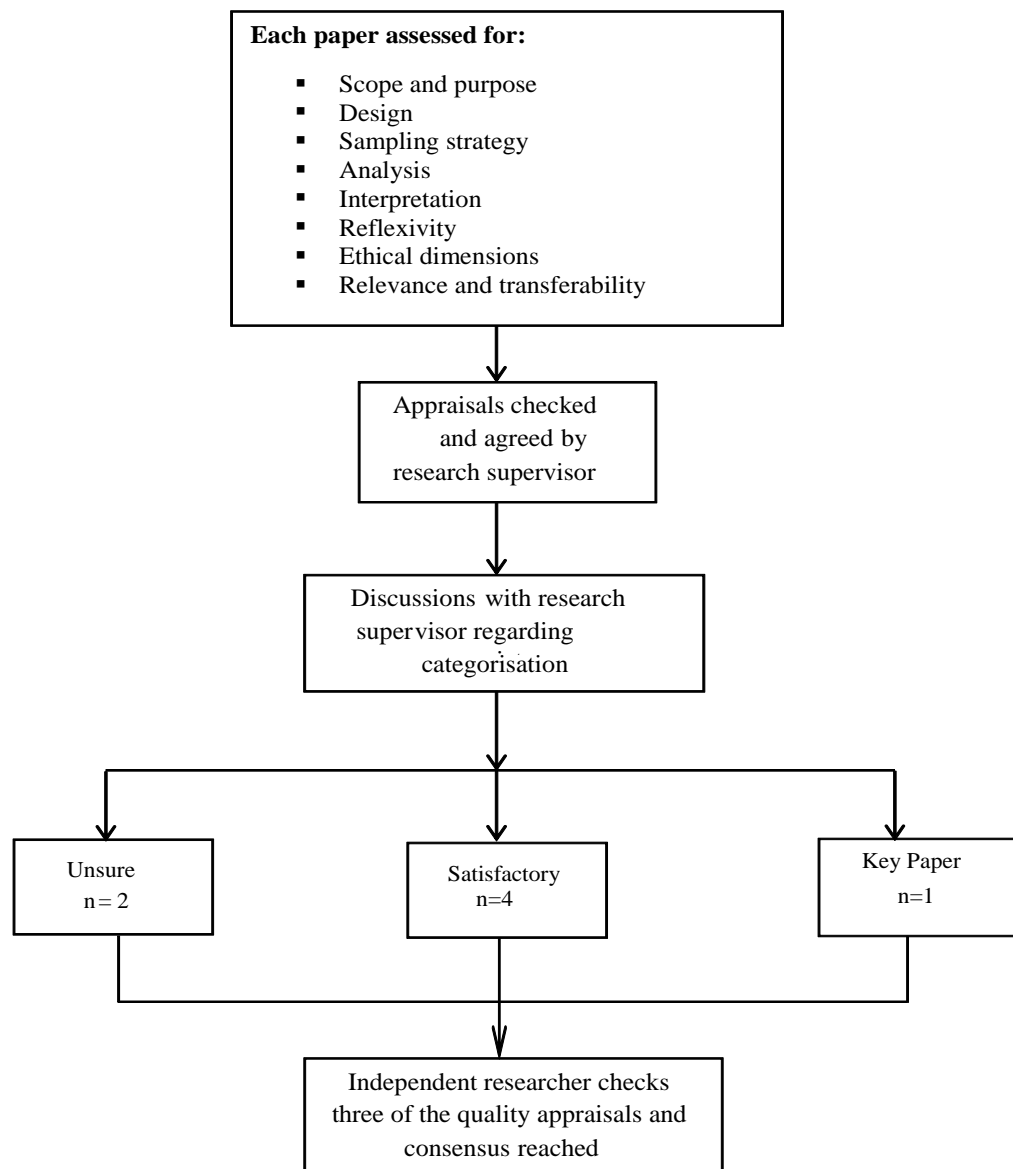


Figure 2. Flow chart of quality appraisal

### Synthesis Process

Seven papers were found. Papers were published from 1998-2007. Countries where participants were recruited from included; Australia, Canada, New Zealand, the UK, and the USA. Studies were either qualitative or had a qualitative element. Analysis included; Descriptive Phenomenology, Grounded Theory, Inductive Thematic Analysis, and Thematic Analysis. The studies assessed for PTSD using the diagnostic tools, PTSD Diagnostic Scale (PDS; Foa, Cashman, Jaycox, & Perry, 1997), Impact of Events Scale

(IES; Horowitz, Wilner, & Alvarez, 1979), or IES-Revised (IES-R; Weiss & Marmar, 1997). Other studies required participants to have received a diagnosis of PTSD from a clinician. For study characteristics see Table 3.

Multiple methods of synthesising qualitative research exist (Dixon-Wood, Booth, & Sutton, 2007). This paper used meta-ethnography (Noblit & Hare, 1988). Meta-ethnographies are inductive and interpretive, and allow authors to make interpretations based on the data. Consequently a deeper analysis, and new interpretations and theoretical understanding can emerge. Noblit and Hare (1988) identified seven stages to undertaking meta-ethnographies. These may occur in parallel or overlap:

1. Identify an intellectual interest that qualitative research might inform
2. Find the literature and decide what is relevant
3. Read the studies
4. Determine how the studies are related
5. Translate studies into each other
6. Synthesise translations
7. Express the synthesis in a way that accounts for the intended audience.

Malpass et al. (2009) developed further methods of translating and synthesising data. They defined first, second and third-order constructs. First-order constructs are participants' interpretations of their experiences, second-order constructs are the investigator's interpretation of these interpretations, and third-order constructs are interpretations of the investigator's accounts (interpretations, of interpretations, of interpretations). This meta-ethnography followed the procedures of Noblit and Hare (1988) and Malpass et al. (2009), leading to the development of three main phases, incorporating Noblit and Hare's (1988) seven stages.

### **1: Defining how the studies are related and identifying second-order**

**constructs.** Phase one incorporates Noblit and Hares' (1988) stages one to four. Once studies were selected and initial readings made the researcher looked for metaphors and key phrases, considering commonalities across papers (see Appendix 3). Next, tables of second-order constructs, including raw data (first-order constructs) from original papers were compiled (see Appendix 4). Further comments about the papers were noted. These contributed towards the development of third-order constructs.

**2: Translating studies into one another.** Phase two incorporates stage five of Noblit and Hare's approach. The second-order constructs were translated across the papers using a table listing terms illustrating the second-order constructs (using authors' original phraseology or accurate paraphrasing). A translation of the meaning of second-order constructs across the studies was then devised, using a table illustrating all second-order constructs with their overarching category (see Appendix 5). This allowed a framework for organising the constructs.

**3: Synthesising translations.** Phase three incorporates stages five to seven of Noblit and Hare's method. The studies were then synthesised. Synthesis was an iterative process, which allowed for further conceptual development. The third-order constructs were developed based on the synthesis, and the researcher's developing interpretations. This led to different categories emerging, as papers examined different aspects of PTSD following a traumatic birth. A *line of argument* was then developed for an overall synthesis (Noblit & Hare, 1988).

Table 3

*Summary of the studies included in the review*

#, Author, year and country	Medical event	Design	Sample and time since event	PTSD measure used	Analysis	Aim	Superordinate themes	Quality appraisal
1) Allen (1998) UK	Traumatic childbirth	Mixed measures: Questionnaire Semi-structured interviews	Questionnaire: n=145 women Interview: n=20 women 10 months post-partum.	Impact of Event Scale (IES; Horowitz, Wilner & Alvarez, 1979)	Grounded theory	Explore the processes during traumatic birth, what mediates PTSD's development and the impact of post-partum adaptation.	Effects to self Relationship with partner Relationship with infant Relationship with others Future pregnancy	Unsure
2) Ayers, Eagle, & Waring, (2006) UK	Traumatic childbirth	Semi-structured interviews	n=6 women (22-37 years) 7 months-18 years post-partum	PDS adapted focus on birth. Retrospective rating	Inductive thematic analysis	To study the affect of traumatic birth on women's relationships	Physical effects of birth Changes in mood and behaviour Fear of childbirth and sexual dysfunction Social interaction and trust Support Strain on relationship Differences in attachment Early feelings about child Later feelings about the child	SAT
3) Ayers (2007) UK	Traumatic childbirth	Questionnaires and interviews	n=25 with PTSD (mean age=29) n=25 no PTSD (mean age=32) Similar birth stories (no PTSD=control) 3 months post-partum.	IES-R and Posttraumatic Stress Symptom Scale	Thematic analysis	To examine women's thoughts and emotions during birth, their processing following birth, and birth memories to consider which factors contribute to the development of PTSD	Thoughts during birth Emotions during birth Postnatal cognitive processing Memories of birth	KP
4) Beck (2004a) New Zealand, USA, UK, Australia (internet)	Traumatic childbirth	Qualitative, internet based stories	n=38 women (25-44 years) 5 weeks-14 years post-partum	Self-reported diagnosis	Descriptive Phenomenology	To describe the lived experience of PTSD following traumatic childbirth.	Going to the movies: Please don't make me go. A shadow of myself: Too numb to try and change. Seeking to have questions answered and wanting to talk, talk, talk	SAT

5) Beck (2004b) New Zealand, USA, UK, Australia (internet)	Traumatic childbirth	Qualitative, internet based stories	n=40 women (25–44 years) 6 weeks-14 years post-partum	Self-reported diagnosis	Descriptive Phenomenology	To explore the experience of birth trauma.	The dangerous trio of anger, anxiety and depression: Spiralling downward. Isolation from the world of motherhood: Dreams shattered. To care for me: Was that too much to ask? To communication with me: Why was this neglected? To provide safe care: You betrayed my trust and I felt powerless. The end justifies the means: At whose expense? At what price?	SAT
6) Beck (2006a) New Zealand, USA, UK, Australia, Canada (internet)	Traumatic childbirth	Internet based stories	n=37 (24-54 years). No time since birth recorded	Self-reported diagnosis 49% of the sample PTSD diagnosis	Descriptive Phenomenology	To examine the lived experience of the anniversaries of traumatic births.	The prologue: An agonising time The actual day: A celebration of the birthday or a torment of the anniversary The epilogue: A fragile time Subsequent anniversaries: For better or worse.	Unsure
7) Nicholls and Ayers (2007) UK	Traumatic childbirth	Semi-structured interviews	n=6 married couples, (six women/six men). (26-50 years) 2-10 years post-partum	PDS adapted to focus on birth. Retrospective rating: at least one couple member had diagnosable PTSD	Inductive thematic analysis	To explore the lived experience of postnatal PTSD and its impact on relationships	Birth factors Quality of care Effects on relationship with partner Effects on relationship with child	SAT

Note: KP=key paper, SAT=satisfactory

## **Findings**

Thirty-eight second-order constructs emerged. Through the synthesis process, papers were split into two groups; factors contributing to the development of PTSD (Group 1) and the lived experience of PTSD (Group 2). Although each study discussed elements in each group, some papers focused on experiences which led to the development of PTSD, and others focused on the current lived experience. Due to differing foci, the groups were synthesised separately before being drawn together to provide a conceptual synthesis of the findings.

The process of translating the studies into each other illustrated that similar experiences were shared across the papers. Translation also demonstrated that there were differences, the most salient being participants' willingness to discuss their experiences. Beck (2004b) found that participants were keen to discuss their experiences; this was not mirrored in other studies. There were also differences in terms of participants' memories of the events and the impact this had on them. Some participants felt if they could forget the event, then they could 'move on' (Beck, 2006), others felt they were stuck because they could not remember the event (Nicholls & Ayers, 2007).

### **Synthesis of Group 1 papers: Factors contributing to the development of PTSD**

Four superordinate themes (third-order constructs) emerged from Group 1; (1) lack of support, (2) loss of control, (3) assault on integrity, and (4) disrupted memories and dissociation. Each is discussed using participants' quotes from the original studies.

#### **Lack of support**

The studies discussed negative experiences of support from professionals and friends and family.

**Poor professional support.** Professional support was experienced as lacking, inappropriate, or poorly communicated (Allen, 1998; Ayers, 2007; Beck, 2004a, 2004b; Nicholls & Ayers, 2007).

*'The first midwife didn't read my birth plan and that upset me.'* (Ayers, 2007, p. 259).

There was a feeling that the women's needs were seen as secondary to the infants', and women suggested that even when professionals viewed the delivery as a 'success' (as both mother and infant had survived) participants felt their needs were minimised or ignored.

*'I would have done anything to have this baby and did everything...All I get told when dealing with the residual emotional effects is, "You should be happy with the outcome."'* (Beck, 2004a, p. 34).

Some participants experienced professionals as 'arrogant', possessing an attitude which suggested they knew what was best for participants without consulting or talking to them. Participants frequently felt that they were not listened too, and often felt ignored by professionals.

*'She [the doctor] was cold, she seemed very resentful that she was called out of her bed at six o'clock in the morning to do the job. She didn't say anything personal to me. Nothing, just 'right, let's stitch this' and examined me.'*

(Nicholls & Ayers, 2007, p. 497).

Experiencing staff as arrogant led participants to have less faith in the professionals' abilities, and led participants to the belief that they (the participants) were not valued, or cared about.

Though most papers (Allen, 1998; Beck, 2004a, 2004b, 2006a; Nicholls & Ayers, 2007) reported communication problems between participants and professional,

Beck's (2004b) paper found that participants wanted to talk to professionals about their experiences following the event. This is unusual, as a characteristic symptom of PTSD is the need to avoid stimuli associated with the trauma.

*'I felt like the Ancient Mariner doomed to forever be plucking at people's sleeves and trying to tell them my story which they didn't want to hear.'* (Beck, 2004b, p. 221).

Overall, participants' experiences of accessing services left them with a pervasive feeling that they could not trust professionals, which negatively impacted on their day-to-day experiences.

**Poor social support.** Participants reported that their experiences were made worse by their partner not being able to offer appropriate support at the time.

*'I wanted him to be big and strong, manly if you like. The fact that he wasn't happy, it made me more scared.'* (Allen, 1998, p. 116).

This left participants feeling vulnerable and isolated at a time they needed someone to be strong for them.

Although some studies reported that participants' significant others were experienced as supportive, this did not seem to have helped protect against the development of PTSD (Beck, 2004a, 2004b).

### **Loss of control**

Participants reported feeling like they did not have control over their experiences during their birth, and they believed this contributed to them developing PTSD (Allen, 1998; Ayers, 2007; Beck, 2004b, 2006a; Nicholls & Ayers, 2007).

*'I strongly believe my PTSD was caused by feelings of powerlessness and loss of control...'* (Beck, 2004b, p. 33).



Participants reported feeling like they had no control over their births, or their bodies, which raised fear for their child.

*‘Fear just overtook the pain because I was scared that something was going to be wrong with him [the baby].’* (Ayers, 2007, p. 259).

Feeling out of control undermined participants’ sense of self, and shifted their views of the world from a place that was understandable and sensible, to one which was uncontrollable and unsafe. Participants were often left feeling frightened and angry.

*‘...it would have been so easy...to have literally lost control and taken out the anger.’* (Ayers, Eagle & Waring, 2006, p.10).

These experiences were compounded by not having faith in the clinicians around them due to the perceived poor communication.

### **Assault on integrity**

Women in Beck’s (2004a, 2006a) and Nicholls and Ayers’ (2007) papers described their experience as equivalent to being raped.

*‘It truly was like being the victim of a violent crime or rape.’* (Beck, 2004b, p. 32).

This illustrates the severity of their experiences, and the extent to which participants were left feeling ‘assaulted’ by people they had needed to trust. Participants reported feeling like they had lost their integrity and they felt disrespected by professionals.

*‘She [the midwife] just had no respect for what I wanted for my body.’* (Nicholls & Ayers, 2007, p. 496).

This left some participants feeling incomplete, helpless and vulnerable, and dependent on professionals they viewed as uncaring.

*‘I don’t feel a whole person, I just feel so invaded by what’s happened’* (Ayers et al., 2006, p. 10).

How participants viewed their bodies after the event was also discussed; participants compared themselves to someone who had been physically assaulted.

*‘...the fact that my vagina was just so mutilated...it’s like a picture of someone that has been battered’.* (Ayers et al., 2006, p. 9).

**Physical pain.** Participants discussed poor pain management and how this impacted on their overall feelings of being treated as sub-human.

*‘...my fear was being in this vortex of pain and screaming in agony...’* (Ayers, 2007, p. 257).

The physical pain that participants experienced did not just affect them in the short-term, but continued to impact on their lives in the following months. This left them feeling devalued as people, as they believed that pain relief was a basic need that had not been met. It also led to difficulties managing their day-to-day existence.

*‘...the fact that I was so physically depressed afterwards, that coloured everything...’* (Ayers et al., 2006, p. 10).

### **Disrupted memories and dissociation**

Participants reported unclear memories of their birth or reported having dissociated during the birth (Ayers, 2007; Beck, 2004b; Nicholls & Ayers, 2007).

*‘...in the end I managed to tune her out and I don’t know what happened, I have no memory of what happened next’.* (Nicholls & Ayers, p. 496).

Participants experienced this as distressing, expressing confusion, disorientation, and frustration caused by their poor recollection or dissociation. Those with disrupted memories wanted to recall the birth to help them understand and process what had happened to them. Yet, participants who described clear memories reported a desire, but inability, to forget their experiences.

*'...loss and pain associated with it seem to reside in every cell of my being, with a memory capacity that serves to never let me forget.'* (Beck, 2006a, p. 19).

These participants believed that if they could forget their birth then they would be able to regain some level of normality.

### **Synthesis of Group 2 papers: The lived experience of PTSD**

Five superordinate themes (third-order constructs) emerged from Group 2 papers; (1) PTSD symptomology, (2) emotional turmoil, (3) continued lack of control, (4) impact on relationships, and (5) future fears. Each is discussed using participants' quotes from the original studies.

#### **PTSD symptomology**

The included studies reported on the lived experience of each PTSD symptom. The symptoms will be discussed in turn.

Re-experiencing was the most widely discussed symptom of PTSD. In particular, participants discussed unpleasant dreams, intrusive thoughts, and flashbacks. Intrusive thoughts and flashbacks were experienced as uncontrollable, and led to participants feeling like they were unable to cope with their life.

*'I have had flashbacks, I was just petrified.'* (Ayers, 2007, p. 261).

Avoidance was discussed, with participants wishing to avoid talking about the birth. This could lead to difficulties with communication between women and their partners.

*'I would get desperately upset if we tried to talk about it, talking about it was painful and awful.'* (Nicholls & Ayers, 2007, p.500).

Participants also discussed their difficulties relaxing (hyper-arousal) and inability to sleep despite feeling exhausted. Nightmares further disrupted participant's sleep, and severely impacted on their lives.

*'I had nightmares of my delivery doctor as a rapist, coming knocking on my door. I also believed when my son was born that the doctor had ripped his head off. These two images were what affected my existence.'* (Beck, 2004b, p. 219).

### **Emotional turmoil**

Participants' lives appeared to be drastically affected by their experiences. Participants expressed feelings including; depression, anxiety and panic attacks, anger, frustration, and suicidal ideation.

*'I was hugely depressed I mean I was suicidal, literally suicidal.'* (Ayers et al., 2006, p. 10).

Participants also noted a change in their ability to cope emotionally, finding that due to the increased emotionality that they were now less able to manage day-to-day stressors.

*'I always used to be patient, but now I fly off the handle.'* (Allen, 1998, p. 120).

Participants often blamed the professionals involved in their care for their strong emotions and PTSD experiences, believing their lived experience of PTSD was partly caused by the inhumane treatment, and a lack of clear communication between professionals and themselves.

*'...I feel such anger at the selfish people who stole the birth of my daughter from me.'* (Beck, 2006a, p. 13).

### **Continued lack of control**

Lack of control continued into participants' experiences of everyday life. Participants described their PTSD symptoms of unwanted memories and flashbacks as uncontrollable and contributing to their feelings of vulnerability.

*'I lived in two worlds, the videotape of the birth and the "real" world. The videotape felt more real.'* (Beck, 2004b, p. 219).

Participants expressed an overall sense that their needs had been disregarded, that they had no control over this during the birth, and that this had led to them believing they had reduced control over their lives.

*'I am amazed that 31/2 hours in the labour and delivery room could cause such utter destruction in my life.'* (Beck, 2004a, p. 32).

Participants reported that their world-view had changed due to them feeling they had no control over their lives.

### **Impact on relationships**

Studies found that participants were left with severe difficulties maintaining relationships with their partners, child, and friends and wider family.

**Partner.** Participants found it difficult to maintain intimate and loving relationships with their partners.

*'I had flashbacks whenever I went into the bedroom...Because we were trying to make love in the same place as the birth...'* (Nicholls & Ayers, 2007, p. 499).

Participants experienced bursts of anger and a tendency to want to avoid closeness which negatively impacted on their relationships (Allen, 1998; Beck, 2006a).

Participants noted that they were angry with their partner for not understanding their distress, took their anger out on their partner, and then felt guilty.

Participants acknowledged that their partners tried to be supportive of their needs, although felt they were unable to provide the right support.

*'...he just wants to try and make it better, and no matter what he does he just doesn't make it better'.* (Ayers et al., 2006, p. 13).

Participants also reported wanting to isolate themselves from their partners and wanting to be alone (Allen, 1998; Ayers et al., 2006; Beck, 2004b, 2006a; Nicholls & Ayers, 2007). This further hindered their relationships.

**Child.** Participants felt they could not cope with caring for their child, or felt disconnected from them.

*‘...I have a strong belief that her real parents will turn up and demand to know why I had been so bad at looking after their child.’* (Beck, 2006a, p. 11).

With participants who had experienced the trauma years previously, it appeared that the difficulties were pervasive, with two papers reporting lasting anxious or avoidant attachments between mother and child (Ayers et al., 2006; Nicholls & Ayers, 2007).

*‘I can’t say I’ve ever felt good with [child].’* (Ayers et al., 2006, p. 15).

**Family and friends.** Many studies reported an impact on participants’ wider relationships. Participants reported heightened anxiety in social situations, and more frustration. Participants spoke of isolating themselves from others, and tending not to see people as frequently as they had prior to the birth.

*‘If I go out to see people or make phone calls I have to really prepare.’*

*Sometimes I just don’t bother.’* (Allen, 1998, p. 121).

Participants also discussed difficulties they had trusting others, which made it almost impossible to maintain social relationships.

*‘I am left now with this anger bubbling around, you know, a mistrust of people...’* (Allen, 1998, p. 120).

Participants reported feeling that though friends and family tried to be supportive, that they did not know how to do this, which led to frustration for the participant and their loved ones. Furthermore, friends and family not knowing how to help appeared to result in further isolation for participants.

*‘And what of my family and friends?...They don’t know what to say, and they cannot make it better, so they end up feeling useless. That’s the real problem’*

*with PTSD. It separates people at the time when love and understanding are most needed.*’ (Beck, 2004b, p. 221).

### **Future fears**

Participants frequently discussed trepidations regarding the future alongside flashbacks.

*‘I feel quite sick at the thought of having another one, going through that again.’*

(Ayers et al., 2006, p. 11).

These may be more accurately described as ‘flashforwards’ as they involve future concerns, and there is debate as to whether they are a symptom of PTSD (Mundy & Baum, 2004). These fears often led to safety behaviours to avoid giving birth again.

*‘Sex, no, because I had a pathological fear of becoming pregnant.’* (Nicholls &

Ayers, 2007, p. 499).

These behaviours negatively impacted on the participants’ lives, for example by contributing to relationship difficulties or breakdowns.

### **Synthesis of Group 1 and 2 papers**

The syntheses of the Group 1 and Group 2 papers were brought together to construct a final line of argument (LOA) synthesis (Noblit & Hare, 1988), illustrating the connections that participants made between why they had developed PTSD, and why it was maintained. The data indicates a complex relationship between participants’ perception of what happened to them during the birth, their (often disrupted) memories of the birth, participants’ perception that they had no control during their birth, and their subsequent experiences. Participants reported being poorly treated by professionals, which led to a strong sense of powerlessness and having reduced control over their lives. Participants appeared to believe that this combination of disrupted memories,

perceived poor treatment, and a lack of power and control contributed to the development of PTSD.

Regarding the lived experience of PTSD, studies frequently reported a pervasive sense of lack of control, and reduced access to social support due to participants' acquired difficulties in trusting others. Participants had a strong sense that the world was no longer safe. Each of these factors contributed to participants feeling unable to process their experiences, which caused them to become 'trapped' by their lived experience of PTSD. Figure 3 illustrates the LOA synthesis.

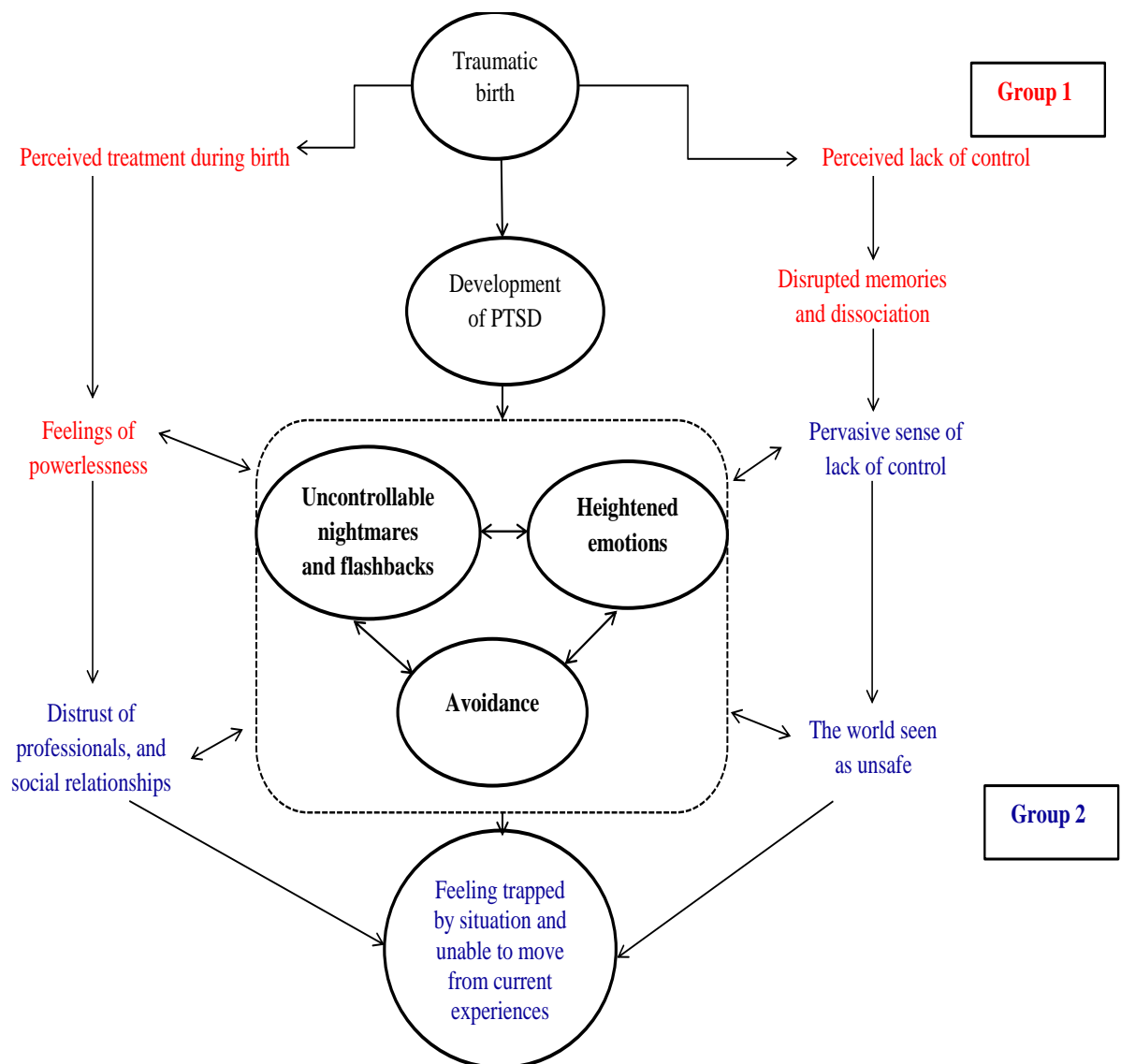


Figure 3. A synthesis of Group 1 and Group 2 papers



## **Discussion**

The aim of this meta-ethnography was to develop a deeper conceptual understanding of the lived experience of PTSD following traumatic birth. This was achieved through synthesising the studies to obtain a deeper understanding of the lived experience of PTSD following traumatic birth. Findings show that living with PTSD following traumatic birth impacts on multiple aspects of women's lives, including their relationships, their emotions, and their ability to feel like they have control over their lives. Overall, the findings suggest that the lived experience of PTSD following birth trauma and non-medical traumas are similar, in that participants frequently experience difficulties with challenging emotions, and maintaining positive relationships due to their PTSD symptoms (Ray & Vanstone, 2009). This similarity is useful, since the evidence-base for PTSD treatments is established on non-medical traumas (Krakow et al., 2001; Nemeroff et al., 2006). The findings will now be discussed in terms of their contribution to current knowledge and theory.

Ehlers and Clark's (2000) cognitive model of PTSD offers a useful framework to consider the current findings. Ehlers and Clark propose that PTSD develops, and is maintained, when individuals' process their trauma in a way that causes them to experience a continued and current sense of threat. Ehlers and Clark posit that this arises as the trauma and/or its sequelae is negatively appraised, and accompanied by a disturbance of autobiographical memory. This may explain why participants in the studies reported memory disruptions as contributing to the development of their PTSD, as memory disruptions prevented them accessing information needed to process the birth. Previous research into road traffic accidents, and assault survivors supports Ehlers and Clark's (2000) model, as it has found that disrupted memories at the time of the

trauma correlate significantly with the severity of PTSD (Ehlers, Mayou, & Bryant, 2003; Halligan, Michael, Clark, & Ehlers, 2003).

With regard to ongoing PTSD symptomology, the studies reviewed emphasised problems with vivid flashbacks, nightmares, or unwanted intrusive thoughts. Papers that assessed for PTSD retrospectively suggested that the difficulties people experienced were long lasting if left untreated (Ayers et al., 2006; Nicholls & Ayers, 2007). Previous research into PTSD following other medical conditions found that participants' PTSD symptoms affected their mental well-being, leading to difficulties trusting others, and resulting in difficulties maintaining intimate relationships (Tedstone & Tarrier, 2003). These findings are mirrored in the current review. Participants also reported feeling vulnerable due to their experiences, which was compounded by feelings of isolation and a reduced ability to seek help for fear that they would not receive appropriate care. Each study reported participants' difficulties with their day-to-day existence, discussing an invasive sense of threat to participants' current and future well-being. Ehlers and Clark's (2000) model would explain this finding by stating that participants continued to experience a sense of threat as they felt unable to challenge beliefs that they could not cope, or that the world was unsafe. This inability was partially due to their symptoms of avoidance, but also due to their negative cognitive appraisals of themselves and the world (Ayers et al., 2006; Beck, 2004b; Nicholls & Ayers, 2007).

Participants experienced fears associated with their futures which negatively impacted on their lives. For example, some women reported such a strong fear of future pregnancy that they employed safety behaviours such as avoiding sex with their partner, which led to substantial relationship difficulties (Beck, 2004b; Nicholls & Ayers, 2007). These fears could be described as 'flashforwards' (Mundy & Baum, 2004) and are not a symptom of PTSD, but may be ascribed to an alternative anxiety disorder. As such, it is

important to carefully assess the specific anxiety symptoms that trauma survivors have to ensure appropriate treatment.

Ongoing emotional distress included; anger, frustration, anxiety, panic attacks, depression, and suicidal ideation. Participants felt this distress was caused by a number of factors including; having uncontrollable re-experiencing symptoms, a belief that they had been mistreated by professionals, and feeling that others did not understand their experiences, thus were unable to offer appropriate support. Due to these experiences it was common for participants to find it hard to communicate their needs. This led to further difficulties maintaining relationships. The reported emotional difficulties appeared closely linked to lack of control, with participants feeling they had no control over their emotions, thoughts, or flashbacks. Feeling unable to control the birth and a pervasive sense of reduced control over their lives were common experiences for participants in the reviewed studies. Foa, Zinbarg and Rothbaum (1992) found that reduced control increased the perceived threat of a situation, therefore enhancing the possibility of developing PTSD.

Feeling betrayed by services was a common experience, and many participants reported difficulties trusting professionals following their birth. Participants blamed services for them developing PTSD in some cases, which contributed to their sense of life being uncontrollable. Feeling let down by services is a factor that earlier research has found contributed to the development and maintenance of PTSD following a medical event (Tedstone & Tarrier, 2003). Ehlers and Clark's (2000) model may explain this, as feeling betrayed by professionals may have led to participants feeling unable to access needed support, which subsequently led to increased levels of perceived threat. Loss of control alongside feeling like their integrity had been attacked

increased individuals' experience of vulnerability, which again created the sensation that the world was unsafe, and that past danger was still present (Dalglish, 2004).

Regarding impact on relationships, participants reported that friends and partners often found it difficult to understand their experiences, and tended to offer unhelpful support. Participants recognised that their own behaviour (due to their PTSD symptoms) had a tendency to impact negatively on their relationships, as they felt unable to trust others, and found it challenging to go out socially. Previous research supports this finding, in that a lack, or perceived lack, of social support is commonly reported in the development and maintenance of PTSD (Andrews, Brewin, & Rose, 2003; Holeva, Tarrier, & Wells, 2001; Ozbay et al., 2007). This is because it reduces sufferers' opportunities to discuss and process their experiences. Women also reported having difficulties bonding with, or caring for their child. Problems with attachment potentially resulted in long-term anxious or avoidant attachments (Ayers et al., 2006; Nicholls & Ayers, 2007).

Due to these findings, it is possible to regard PTSD as a self-perpetuating condition, as avoidance is a characteristic symptom of PTSD. Avoidance contributes to sufferers not fully processing the birth, by not revisiting it. Furthermore, by trying to avoid thinking about the birth, it ensures the sufferer can think of little else, thus worsening the experience of intrusive thoughts and flashbacks (Ehlers & Clark, 2000).

### **Relating the current findings to recent birth trauma reviews**

The current findings broadly mirror those of earlier reviews of birth trauma (Beck, 2011; Elmir et al., 2010). As in the current review, an array of challenging emotions were noted in the earlier reviews, and each discussed the impact that perceived poor medical care had on women psychologically – including having a pervasive sense

of distrust of health professionals. Each review also found that women were left with difficulties attaching to their children and experienced wider relationship difficulties.

However, there are also notable differences. For instance, Beck (2011) specifically discussed difficulties with breastfeeding in one theme. This was not noted in the current review or Elmir et al.'s (2010) review. Beck included a paper which solely discussed the impact of traumatic birth on breastfeeding in her review, which may explain this finding (this was the only paper she quoted in the section). A further difference is that both the Elmir and Beck papers have positive themes. Elmir et al. (2010) discusses 'strength of purpose: a way to succeed as a mother', whereas Beck discusses breastfeeding as a 'healing' and discussed how subsequent births had allowed a positive experience, which helped women overcome their traumatic births. None of the themes in the current review could be described as 'positive'. There are a couple of possible explanations for this discrepancy in the findings. With regard to Elmir et al.'s (2010) theme "strength of purpose", the theme may have emerged as they did not focus on PTSD following birth, but birth that was traumatic. The current review focused explicitly on PTSD following traumatic birth. With regard to Beck's (2011) positive themes, she included a paper which the current review excluded due to it solely focusing on breastfeeding (Beck & Watson, 2008) and another paper which did not state whether participants were screened for PTSD or whether participants had received a diagnosis of PTSD (Beck, 2006b). Due to this, it is possible, that the papers Beck included reported these positive experiences, which were not reported by the papers included in the current review. A further difference is that the current study noted memory disruptions as important to the development of PTSD following traumatic birth. This was not reported in either of the other reviews, which did not relate their findings to cognitive models of PTSD.

## **PTSD and other medical conditions**

Despite the growing amount of quantitative research indicating that PTSD can develop following medical conditions and medical events (Andrykowski, Cordova, McGrath, Sloan, & Kenady, 2000; Field, Norman, & Barton, 2008) there is limited qualitative research into the lived experience of PTSD following medical events and conditions. However, qualitative research has explored the lived experience of PTSD following intensive care unit (ICU) treatment resulting from serious illness (Corrigan, Samuelson, Fridlund, & Thome, 2007). Corrigan et al. (2007) noted that participants frequently reported heightened emotionality, anger at poor support from services, and pervasive difficulties maintaining social relationships. Corrigan et al. (2007) also found that participants reported reduced control over their lives due to the uncontrollable nature of flashbacks and nightmares. As such, there appears to be parallels between the experiences of PTSD resulting from ICU treatment and traumatic birth. Similarities have also been noted from quantitative research into PTSD following cancer treatment, and myocardial infarction (MI). For instance, research suggests that participants who experience PTSD following MI or cancer treatment can experience challenging emotions, such as depression, anxiety, anger and suicidal ideation (Doerfler, Pbert, & DeCosimo, 1994; Mundy et al., 2000). Studies have also noted that some participants had difficulties maintaining intimate relationships following the development of PTSD due to their cancer diagnosis and treatment (Hodgkinson et al., 2007; Kornblith & Ligibel, 2003). These similarities are interesting, and suggest it is important to undertake further qualitative investigations into the lived experience of PTSD resulting from different medical conditions or events.

## **Limitations**

A number of limitations should be noted when interpreting this review's findings. First, the studies reviewed used different ways of assessing PTSD. Some used the validated tools PDS (Ayers et al., 2006; Nicholls & Ayers, 2007) or IES-R (Ayers, 2007), but others relied on participants stating whether they had been diagnosed with PTSD (Beck, 2004a, 2004b, 2006). This may be problematic, as it is possible that some participants who experienced a traumatic birth, may not have received a formal PTSD diagnosis, but participated due to believing that their experience of 'traumatic birth' was equivalent to developing PTSD. One study used the Horowitz et al. (1979) version of the IES (Allen, 1998). This was developed before hyper-arousal, detriment to functioning, and the timeframe needed to have passed were included in the criteria for a PTSD diagnosis. Consequently the tool is not accurate for diagnosing PTSD under the DSM-IV (American Psychiatric Association, 1994). A further limitation is that two papers (Allen, 1998; Beck, 2006) included some participants who were not diagnosed as having PTSD and analysed the data together. This is problematic as not all data referred to a PTSD experience.

Second, in two studies (Ayers et al., 2006; Nicholls & Ayers, 2007) the length of time since the traumatic event was considerable. In the case of Ayers et al. (2006) this ranged from seven months to 18 years post-partum, and for Nicholls and Ayers (2007) it was two to 10 years post-partum. In both cases participants were asked to consider their symptoms at the time of the birth rather than current symptoms, leading to difficulties in accurate recall.

Third, a restricted amount of reflexivity was noted in the papers used in the review. Reflexivity is an awareness that researchers contribute to the meaning uncovered during qualitative research (Nightingale & Cromby, 1999). Most papers (Allen, 1998; Ayers, 2007; Ayers et al., 2006; Beck, 2006; Nicholls & Ayers, 2006) did

not discuss reflexivity. This is problematic, as it does not consider that alternative data may have emerged with different researchers.

### **Clinical implications**

The review reveals that women's experience of PTSD following traumatic birth causes a broad range of psychosocial difficulties. Clinicians need to be aware of this and undertake routine assessments of PTSD following birth. This should occur even if clinicians do not view the birth as unusual, since the review found participants can experience PTSD even when clinicians view the birth as routine. As part of this assessment women should be asked whether intrusive thoughts/images they experience are associated with the birth itself, or future events. This is because the review illustrates that some participants experience 'flashforwards' as well as 'flashbacks'. Flashforwards may indicate that the woman has health anxiety as opposed to PTSD. This is important as the protocols for treating PTSD and health anxiety differ (National Institute for Health and Clinical Excellence, 2005, 2007).

Furthermore, the review demonstrates the need for good communication between services and women throughout the care pathway. This is partially to help prevent the development of PTSD, but also because the review highlighted that women may find it difficult to trust professionals following a traumatic birth. Consequently, services need to focus on engagement with women to ensure they can access appropriate support.

The review also found that attachment difficulties can emerge. Consequently it is important to offer support to mothers following traumatic birth to help ensure secure attachments develop and are maintained.

### **Future research**



The findings indicate that further research is needed into the lived experience of PTSD following a range of medical events such as stroke, MI, HIV diagnosis, and cancer treatment. Such research could have important theoretical and clinical implications for the definition and treatment of PTSD. The review illustrated that some people experience 'flashforwards' as well as 'flashbacks'. This may indicate that people develop health anxiety as well as PTSD following medical events. Future research could explore the phenomenology of people's intrusive thoughts following medical events in greater detail to distinguish between PTSD and health anxiety symptoms.

### **Conclusion**

The lived experience of PTSD following traumatic birth impacts on multiple aspects of individuals' lives; including mood, relationships, and overall well-being. This meta-ethnography illustrates the need for clear, person-centred communication with women throughout their medical care. It also highlights the importance of giving women time to understand what has happened to them, and to allow the chance to ask questions regarding this. It illustrates that support would be useful soon after traumatic birth to ensure that women's needs are carefully assessed and appropriate support is provided.

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## **Section 2**

### **Empirical Study**

**A qualitative investigation into people's experience of Post-Traumatic Stress Disorder following stroke**

### Abstract

**Introduction.** There is growing quantitative literature exploring aspects of Post-Traumatic Stress Disorder (PTSD) following stroke. However, the appropriateness of a PTSD diagnosis following stroke, as opposed to an alternative anxiety disorder, has been questioned. To answer this question, qualitative research is required to explore the lived experience of PTSD following stroke.

**Aim.** The main aim was to explore stroke survivors' experiences of PTSD following their stroke, focusing on whether the intrusive thoughts they experience are consistent with PTSD, health anxiety, or a combination of both. Survivors' experiences of avoidance and hyper-arousal symptoms of PTSD were examined as were their memories of their stroke.

**Method.** Semi-structured interviews were conducted with stroke survivors (n=9) who fulfilled the PTSD criteria as assessed by the PTSD Diagnostic Scale (Foa, Cashman, Jaycox & Perry, 1997). Recruitment was via stroke clinics and intermediate care. Interpretative Phenomenological Analysis was used to analyse data. Quality control methods were used during analysis to promote validity and rigour.

**Results.** Four superordinate themes emerged; (1) the experiences and maintaining factors, (2) loss, (3) support, and (4) positivity.

**Conclusion.** The study illustrates that stroke survivors experienced a complex range of psychosocial difficulties, including challenging emotions and a sense that their lives had become uncontrollable. Participants also discussed loss in multiple domains. Participants reported flashforwards as well as flashbacks. This may suggest that participants experience co-morbid health anxiety and PTSD, indicating a need for careful assessment for anxiety conditions following stroke.

**Key words:** PTSD, stroke, IPA, qualitative study.

## **Introduction**

### **Stroke**

Stroke is the third most common cause of death in England with over 110,000 people having a stroke annually (The Stroke Association, 2010). There are two main types of stroke; ischaemic stroke and brain haemorrhage. Ischaemic strokes occur when there is a blockage in an artery that transports blood to the brain. Haemorrhagic strokes arise when a blood vessel bursts and bleeds into the brain. Stroke costs the NHS over £3 billion per annum (Department of Health, 2010). The risk of stroke significantly increases over the age of 55 years, with the risk doubling with every subsequent decade (Department of Health, 2010). Although stroke can affect people of all ages, most people experiencing stroke are older adults.

The variety of disabilities caused by stroke is vast. Physically, people can experience damage to motor neurones, resulting in paralysis, limb weakness, and numbness. Strength or movement can be difficult to regain, resulting in difficulties with fine movement such as writing (The Stroke Association, 2009). Stroke survivors can also be left with cognitive deficits including attention difficulties, difficulties in processing information, and memory loss. Speech difficulties are often associated with stroke, like aphasia whereby an individual struggles to locate words and form sentences. Psychological problems including depression, anxiety, apathy, and emotional lability can also occur (The Stroke Association, 2009). There is also increasing evidence that Post-Traumatic Stress Disorder (PTSD) can affect people who have had a stroke (Field, Norman, & Barton, 2008; Norman, O'Donnell, Creamer, & Barton, 2012).

### **Post-Traumatic Stress Disorder**

PTSD is an anxiety condition which develops following a 'traumatic' event. The Diagnostic and Statistical Manual of Mental Disorders-IV (DSM-IV; American Psychiatric Association, 1994) states that for PTSD to be diagnosed Criteria A-F need to be met. Criterion Ai states symptoms need to develop following exposure to an extreme traumatic event involving actual/threatened death or serious injury, or a threat to self-integrity to self or others. Criterion Aii requires feelings of intense fear, helplessness or horror to be experienced. Criteria B-D are the presence of the symptoms re-experiencing, avoidance and general numbing of responsiveness, and hyper-arousal. Criterion E states symptoms must be present for at least one month, and Criterion F states symptoms must have a substantial negative impact on social, occupational or other areas of functioning.

Ehlers and Clark's (2000) cognitive model of PTSD posits that PTSD develops and is maintained when individuals process their trauma in a way that causes them to experience a continued and current sense of threat. They state that the perceived threat can be external (e.g. the world is a more dangerous place) or internal (e.g. the person no longer views themselves as competent). They suggest that the perceived threat arises as trauma and/or the subsequent events are negatively appraised, and accompanied by a disturbance of autobiographical memory. There is growing evidence to support this. For instance evidence that negative appraisals contribute to the development of PTSD comes from Foa, Ehlers, Clark, Tolin and Orsillo (1999). Foa et al. (1999) examined the impact that negative cognitions about the self, negative cognitions about the world, and self-blame had on the development of PTSD. They found significant correlations between all three negative appraisals and the severity of PTSD symptoms following traumas including accidents, assaults, and sexual assaults. Research has also examined the impact of negative cognitive appraisals following traumatic medical events (Agar,

Kennedy, & King, 2006; Field et al., 2008; Kangas, Henry, & Bryant, 2005). Agar et al. (2006) and Field et al. (2008) found that negative self-appraisals and negative appraisals of the world correlate with more severe PTSD, though in contrast to other types of trauma, self-blame was not found to be significantly correlated with PTSD following medical events.

Evidence that dissociation and disrupted autobiographical memories contribute to the development of PTSD comes from Murray, Ehlers and Mayou (2002). They conducted work with road traffic accident survivors who had developed PTSD, and found dissociation and incomplete memories of the event were strong predictors of PTSD. Similar findings have been reported by Halligan, Michael, Clark and Ehlers (2003) with assault victims. Murray et al. (2002) and Halligan et al. (2003) suggested that disrupted memories are linked to the development of PTSD as they hinder effective processing of the trauma experience. This supports the Ehlers and Clark (2000) model.

### **Medical events and PTSD**

Historically, PTSD research has focused on events such as war, surviving a natural disaster, and physical and sexual assaults. However, more recently it has been recognised that medical events such as stroke, heart disease, and being diagnosed with HIV may trigger PTSD as they are unexpected, uncontrollable and can be life-threatening (Andrykowski, Cordova, McGrath, Sloan, & Kenady, 2000; Field, et al., 2008; Whetten, Reif, Whetten, & Murphy-Mcmillan, 2008). Studies have reported the prevalence of PTSD after stroke to range from 3% (Sharkey, 2007) to 31% (Bruggimann et al., 2006). Spindler and Pedersen (2005) found the estimated prevalence rate for PTSD after heart disease ranged from 0-38%. This suggests that PTSD prevalence rates among stroke survivors are in line with other life-threatening conditions.

Norman et al. (2012) conducted a review into the prevalence and correlates of PTSD following stroke. They found the strongest correlates of PTSD symptom severity were anxiety, depression, and negative cognitive appraisals. This offers further evidence that negative cognitive appraisals contribute to the development and maintenance of PTSD, but also highlights that stroke survivors can experience a range of psychological distress following stroke. Impaired psychological well-being can hinder stroke survivors' physical recovery (Lewis, Dennis, O'Rourke, & Sharpe, 2001; Morris, Raphael, & Robinson, 1992; Wilz, 2007), thus highlighting the need to carefully assess stroke survivors' psychological state to ensure appropriate interventions.

Mundy and Baum (2004) reviewed literature focusing on PTSD and medical conditions including heart transplants, receiving a cancer diagnosis, and HIV. They argued that although people with medical conditions may experience PTSD-type experiences, the intrusive thoughts and images they experienced may be more accurately described as "flashforwards" as opposed to "flashbacks". For instance, the images and invasive thoughts that some individuals reported were associated with their futures as opposed to their initial trauma. Mundy and Baum questioned the appropriateness of a PTSD diagnosis and raised the possibility that the trauma of a life-threatening illness may lead to generalised anxiety disorder (GAD) as opposed to PTSD. Consequently, they recommended a phenomenological study into the nature of people's experience of intrusive thoughts to examine whether these were associated with the initial trauma or future events. Mundy and Baum's paper is interesting as it questions whether it is PTSD or GAD that develops following medical trauma. However, the DSM-IV (American Psychiatric Association, 1994) states that GAD is characterised by excessive worry about a number of activities and events. Mundy and Baum (2004) found that the reported flashforwards specifically

related to future fears associated with participants' health. Pervasive anxiety about an individual's health is more accurately defined as health anxiety (Salkovskis, Rimes, Warwick, & Clark, 2002). This may suggest that the reports of flashforwards Mundy and Baum (2004) noted are indicative of health anxiety as opposed to PTSD or GAD.

Despite Mundy and Baum's (2004) recommendation to undertake qualitative research in PTSD and medical traumas, and the growing amount of quantitative research into stroke and PTSD (Bruggimann et al., 2006; Field et al., 2008; Merriman, Norman, & Barton, 2007), no qualitative research into PTSD after stroke has been conducted to date. Nonetheless the importance of individuals' understanding of their stroke experience has been explored qualitatively (Manzo, Blonder & Bums, 1995). Manzo et al. (1995) examined the content of stroke survivors' and their spouses' narratives. Stroke survivors tended to have poor memories of their stroke and the surrounding events, whereas, their partners had clearer memories of the event. Manzo et al. found that combining the narratives could help stroke survivors understand the stroke experience, which aided their psychological recovery. The authors interpreted this as highlighting the beneficial nature of social support during stroke recovery. However, it may also be interpreted as illustrating the need to gain a more complete memory of the stroke experience to assist in understanding this experience, as discussed by Ehlers and Clark (2000).

### **Qualitative research into PTSD following medical events**

Qualitative research has been conducted with people experiencing PTSD following medical events including Intensive Care Unit (ICU) treatment (Corrigan, Samuelson, Fridlund, & Thome, 2007), traumatic childbirth (Beck, 2004a, 2004b, 2006; Nicholls & Ayers, 2007), and children with cancer and their families (Patterson, Holm, & Gurney, 2004). The qualitative research surrounding traumatic birth and ICU



treatment revealed that participants experienced a complex range of psychosocial difficulties resulting from their experiences of PTSD. In particular, participants discussed feeling like they had reduced control over their lives due to the uncontrollable nature of flashbacks and nightmares (Beck, 2004a, 2004b; Corrigan, et al., 2007; Nicholls & Ayers, 2007). Although some studies found that participants discussed future fears, these were not discussed in relation to the appropriateness of a diagnosis of PTSD (Corrigan et al., 2007; Nicholls & Ayers, 2007).

Participants also reported experiencing strong emotional states, including anger, anxiety and panic (potentially linked to hyper-arousal), low mood, and suicidal ideation (Beck, 2004a, 2004b; Corrigan, et al., 2007; Nicholls & Ayers, 2007). The combination of these experiences caused participants to have difficulties maintaining social relationships, and led to a distrust of professionals, due to their perceived role in the development of participants' PTSD (Beck, 2004a, 2004b; Corrigan et al., 2007; Nicholls & Ayers, 2007). Studies also reported memory disruptions/ dissociation during the trauma, which participants felt contributed to the development of their PTSD (Corrigan et al., 2007; Nicholls & Ayers, 2007).

The findings from qualitative research into PTSD following ICU treatment and birth trauma indicates a need for a deeper understanding of the lived experience of PTSD following other medical events. Consequently there is a need to explore the phenomenological experience of PTSD following stroke. Particular consideration needs to be given to whether participants' intrusive thoughts are consistent with a diagnosis of PTSD or health anxiety. In line with cognitive models of PTSD, the current study will also explore individuals' memories surrounding their stroke and the subsequent events as the literature suggests this may contribute to the development and/or maintenance of PTSD.

## **Aims**

- To examine stroke survivors' overall experience of living with PTSD
- To explore survivors' memories of their stroke
- To consider whether stroke survivors' experiences are consistent with a diagnosis of PTSD, a type of health anxiety, or a combination of both.

## **Method**

Participants were recruited from another study examining the relationship between disturbances in autobiographical memory and PTSD symptom severity.

## **Screening tool**

Foa, Cashman, Jaycox and Perry's (1997) PTSD Diagnostic Scale (PDS) was used as to assess for PTSD. This was adapted for use with stroke patients (see Appendix 11). The PDS assesses whether people meet Criteria A-F. For Criteria B-D it asks a series of questions about each symptom. Participants need to rate at least one experience for each symptom. Foa et al. (1997) found the PDS to have good internal reliability, alongside good sensitivity (0.89) and specificity (0.75) as compared to a structured clinical interview to assess PTSD.

## **Procedure**

Stroke survivors attending Sheffield Teaching Hospital's (STH) six-week follow-up stroke clinic were approached with an information sheet outlining the first study. This information sheet mentioned the possibility of participating in the current study if eligible (see Appendix 8). Participants who met PTSD criteria, as assessed by the PDS, and indicated that they were willing to be interviewed were sent an information sheet outlining the current study (see Appendix 9), and a return slip to provide contact details (Appendix 10) with a stamped addressed envelope. Respondents were contacted by the researcher, who arranged a time and place to conduct the interview. Upon meeting any

questions were answered, and participants gave informed consent prior to being interviewed (see Appendix 12). The recorded interviews were transcribed by the researcher or University of Sheffield approved transcribers.

Additional stroke survivors were approached at STH's Intermediate Care unit, which offers inpatient care to 15 stroke patients. Patients were informed by unit staff about the research and given the study information sheet. If they were interested, the screening questionnaire was completed. If eligible, they were invited to take part, and given time to ask questions.

All interviews took place one week to one month following the screening. Once individual interviews had been analysed, the participant was contacted and offered the opportunity to check their emergent themes.

### **Inclusion and exclusion criteria**

Participants were included if they had had a stroke, met the criteria for PTSD as assessed by the PDS, could complete the PDS themselves or with help (from the researcher, a friend, or relative), could provide informed consent, and were over 18. Participants were excluded if they were unable to complete the screening questionnaire due to cognitive impairment or severe aphasia, or were not fluent in English. People with experience of mental health difficulties and substance misuse were not excluded, nor were people who have had multiple strokes or previous traumas. However, if present, these were considered during data analysis.

### **Sample**

Forty-eight stroke survivors were screened from the stroke clinics. Eleven met PTSD criteria (23%), and six agreed to be interviewed (55% of those meeting criteria). Seven of the 15 patients from the intermediate care unit were screened, with three meeting PTSD criteria and agreeing to be interviewed. The total sample consisted of

nine participants: four men and five women. Eight participants were white British, and one was Asian, originating from Pakistan. Participants ranged in age from 35-80 years (mean=61.67; SD=13.05), and the time since their stroke ranged from five weeks to three years (see Table 1). Participants' PTSD symptom severity scores were mild (n=1), moderate (n=5), or moderate-severe (n=3). Their impairment in functioning score due to their PTSD were mild (n=1), moderate (n=2) or severe (n=6).

The four participants whose strokes were more than three months ago had requested further clinic appointments, which is why they presented at a six-week follow-up clinic.

Table 1

*Participant demographic details*

#	Sex	Age	Ethnicity	Time since stroke	Number of strokes	PDS profile	
						Functioning impairment	Symptom severity
1	Male	63	South Asian	8 weeks	1	Severe	Moderate
2	Female	71	White British	3 months	1	Severe	Moderate-severe
3	Female	71	White British	15 months	1	Severe	Mild
4	Female	51	White British	6 weeks	1	Severe	Moderate
5	Male	61	White British	8 weeks	1	Moderate	Moderate
6	Male	35	White British	34 months	1	Severe	Moderate
7	Female	80	White British	5 weeks	2	Mild	Moderate
8	Male	58	White British	18 months	1	Moderate	Moderate-severe
9	Female	65	White British	38 months	1	Severe	Moderate-severe

**Data collection**

Data collection was via semi-structured interviews, which lasted between 15-86 minutes. Participants were aware that they could request breaks in the interview. The interview schedule was constructed using Smith, Larkin and Flower's (2009) guidelines. It started with an open question asking participants to describe their stroke, before exploring their memory of the stroke, and the different symptoms of PTSD.

Table 2 gives an overview of the interview questions (see Appendix 7 for additional

prompts). The researcher made it explicit that each question referred to the participant's experiences in relation to their stroke.

The researcher was aware that qualitative interviewing can lead to difficult emotions being expressed. As such she employed empathetic listening skills to encourage participants to express their insights into their experiences.

Table 2

*Interview topics*

Question number	Question
1	Please tell me about your (most recent) stroke.
2	How complete do you feel your memory of your stroke is?
3	Do you have any problems when trying to remember your stroke?
4	Please tell me about any memories, worrying thoughts and/or images that suddenly pop into your head (related to your stroke).
5	Please tell me about times when you've felt like avoiding somewhere/something/someone associated with your stroke.
6	Please tell me about times when you've felt emotionally numb, or like you were watching situations instead of being involved with them.
7	Please tell me about times that you've had difficulties relaxing.
8	Please tell me about any other experiences you've had.

## Analysis

Interpretative Phenomenological Analysis (IPA) was used to analyse data. IPA does not seek to test existing hypotheses; instead it compares findings to existing theories, and may in some cases lead to further theory development. Larkin and Thompson (2012) highlight that IPA is phenomenological as it is concerned with trying to understand the lived experience, examining how each participant makes sense of their life. IPA is interpretative as it states the researcher cannot fully understand another person's phenomenological experience. Reflexivity is considered to be important in IPA, as the researcher will develop preconceptions about participants, and participants will form ideas about the researcher, which will impact on the narratives shared (Larkin & Thompson, 2012).

Each interview was audio-recorded, and immediately after the interview, the interviewer wrote notes on the participant's body-language and their apparent attitude towards the interview process. Each audio-recording was transcribed verbatim. Transcripts were read and re-read alongside the recorded interviews and notes made following the interviews. This was to aid immersion in the data. Line-by-line analysis was undertaken to uncover descriptive and conceptual perspectives. Exploratory comments regarding the researcher's thoughts about meaning behind participant statements were noted (see Appendix 13). Emerging themes were identified that aimed to capture the meaning of the data and the researcher's interpretation of it. Themes were clustered and restructured according to frequency, prominence and conceptual fit; these were checked with the original transcripts to ensure analysis remained close to the data. Participants were invited to verify whether they agreed with the emergent themes from their interview. Four participants did this (see Appendix 14).

IPA needs each case to be examined individually to ensure each participant's account is gathered. The researcher is not meant to be influenced by previous participants' accounts. To promote this, the researcher kept a reflexive journal to 'bracket' interviews, thus encouraging objectivity between cases (Smith et al., 2009). Cases were only compared once each had been thoroughly analysed. A table was drawn-up to help draw links across the interviews (see Appendix 15). A diagram was also developed to help define themes, and to illustrate links between them (Figure 1).

## **Ethics**

Ethical approval was obtained from the East Yorkshire and North Lincolnshire Research and Ethics Committee, and Research and Development (R&D) was approved via Sheffield Teaching Hospital (see Appendix 6). The researcher was conscious of the need for sensitivity throughout the research process. She ensured that participants were

aware of confidentiality and its limitations. All participants understood that the researcher would contact their GP should she be concerned about their emotional well-being. The researcher also ensured that the contact details for a voluntary support group (The Stroke Association) were available to all participants.

### **Quality assurance**

Mays and Pope (2000) recommend the following to promote quality assurance.

**Participant verification.** As stated, in order to verify analysis of participants' accounts, they were invited to check their emerging themes. This process allowed participants the opportunity to comment on the researcher's interpretations of their accounts. Their comments were taken into account and the analysis was revised as necessary.

**Reflexivity.** Nightingale and Cromby (1999) define reflexivity as researchers needing an awareness of their contribution to the meaning uncovered during qualitative research. Shaw (2010) suggests that it is not possible to remain objective. Thus to be reflexive, researchers need to explore the ways their involvement impacts on, and informs the work undertaken. The current researcher is a Caucasian woman who was 30-31 years-old when conducting the interviews. She was also mindful that she would be younger than participants. These factors may have impacted on participants' views of her. The researcher was also mindful of her professional and personal experience of being with people following stroke (she had been on placement in a stroke service, and her father had experienced a Transitory Ischaemic Attack). This led to preconceptions about what it is like to experience stroke and its consequences. These issues were explored and considered using a reflexive journal (see Appendix 17) to ensure that emergent themes were based on the data, not pre-existing beliefs. The researcher also

came from a social constructivist standpoint, in that she believed people's realities are partly constructed through the telling and receiving of narratives.

**Evidence grounded in case examples.** All data gathered and analysed was grounded in each case example. The reflexive journal ensured that earlier analysed interviews did not 'interfere' with the analysis of subsequent interviews.

**Interview coders.** The researcher undertook coding of the interviews. Her research supervisor monitored coding reliability and further checks were undertaken by the researcher's peer qualitative researchers (see Appendix 18 for peer checking protocol). Any disagreements were discussed and explored until an agreement was met. This process allowed a deeper analysis of data and ensured that five of the interviews were analysed by two independent researchers.

**Triangulation of analysis.** Alongside using participant verification, and having multiple interview coders, an expert in the field was consulted about the themes arising from the interviews. Feedback from these methods was used to develop and enhance interpretation of the data.

**Service user involvement.** Service users were not involved when the initial interview schedule was devised, due to time-restraints. However, stroke survivors were contacted via a local stroke support group, and consulted in relation to interview amendments. This ensured interview relevance and appropriate language use. It also informed good practice for undertaking interviews, for instance, the group felt it was important for participants to take breaks if needed. The amended interview schedule was piloted on someone who had had a stroke, though had not developed PTSD.

## Results

Despite initially aiming to recruit participants who had experienced their stroke within the previous two months (recruitment was via six-week follow-up clinics and



intermediate care), four participants had experienced their stroke 15 months to 3 years earlier. Consideration was given as to whether to analyse the data separately. As emergent themes were strong across interviews despite the range of time since stroke, it was decided not to look at data separately.

One participant who experienced her stroke three years earlier was later found to have had an arteriovenous malformation. This is a congenital condition which led to her experiencing a bleed, which resulted in equivalent damage to a stroke. It felt appropriate to include her experiences as she was treated by the stroke team and continues to receive support from statutory and voluntary stroke organisations.

Four super-ordinate themes emerged: (1) the experiences and maintaining factors, (2) loss, (3) support, and (4) positivity. Figure 1 illustrates the links between each theme and sub them, whilst Table 3 shows emergent themes. Each theme is discussed using illustrative quotes from the participants' accounts.

Table 3

*Table of emergent themes*

<b>Super-ordinate themes</b>	<b>Sub-themes</b>
The experiences and maintaining factors	Intrusive thoughts, flashbacks and flashforwards The impact of avoidance Changed emotions Life as uncontrollable and hopeless Memories surrounding the stroke Needing an explanation
Loss	Identity shifts and loss of independence Loss of ability Loss of roles Loss of social-self
Support	Negative service experience Positive service experience Ineffective social support Helpful social support
Positivity	

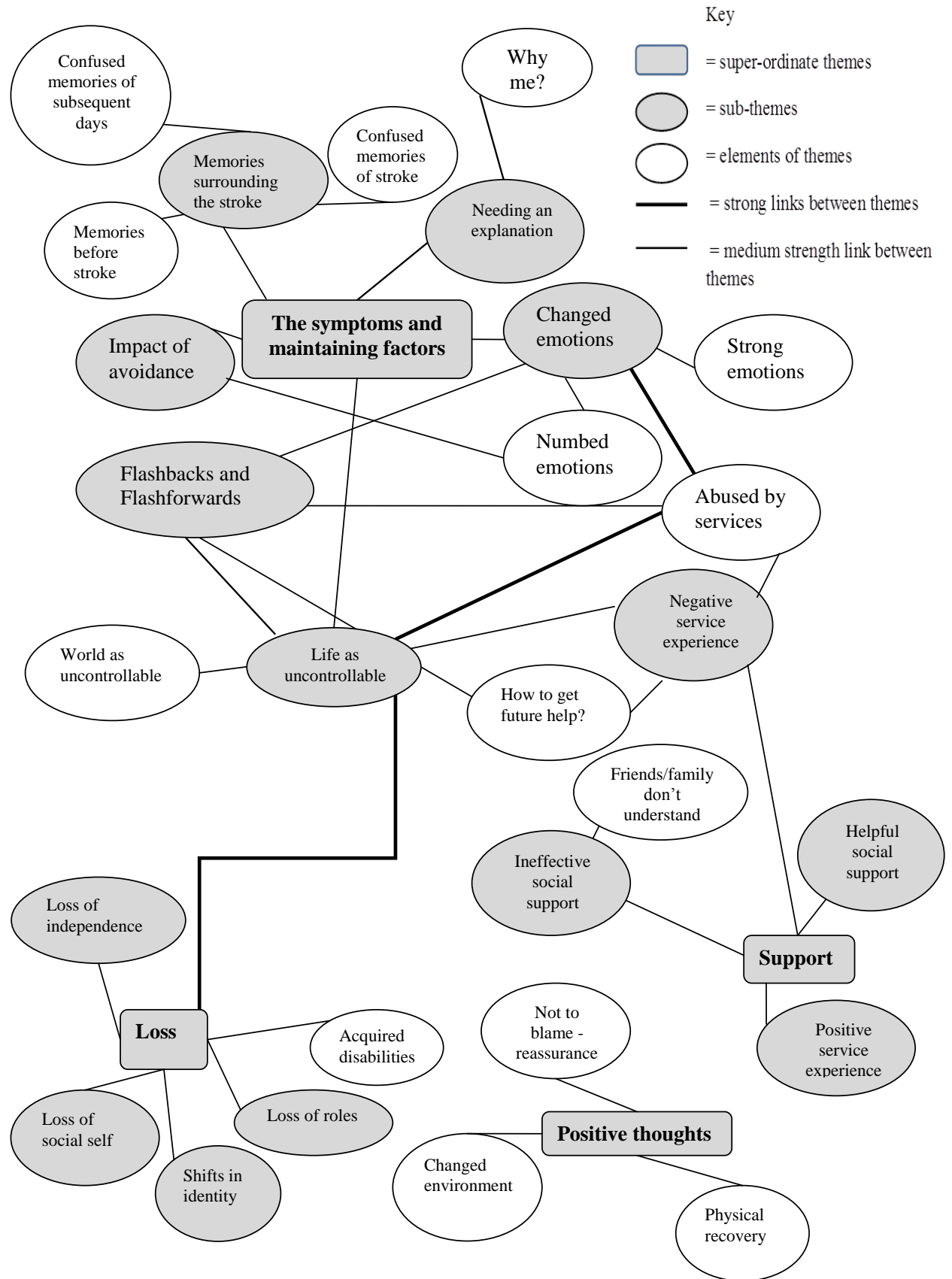


Figure 1. Diagram illustrating links between themes

## 1: The experiences and maintaining factors

Participants discussed their day-to-day experiences and aspects they believed contributed to the maintenance of their emotional situation.

**1.1: Intrusive thoughts, flashbacks and flashforwards.** Participants discussed intrusive thoughts associated with their stroke or the subsequent events. Participants discussed a range of flashbacks or intrusive thoughts they had. These included how they had been treated by services or professionals. For instance one participant had recurrent flashbacks to lying on the floor waiting to be sent an ambulance, whilst the operator questioned her need for an ambulance.

*P2: ‘...I don’t consider myself a poor old lady but I’m thinking of some poor old woman lying on the floor and somebody’s playing God...’*

Some experienced worrying thoughts related to whether they could have picked up on any indications that they were going to have a stroke, thinking they could potentially have prevented it.

*P9: ‘Sometimes I wonder if there were things, little warning signs, that I could have picked up on.’*

Others experienced flashbacks to their actual stroke, or subsequent care.

*P6: ‘...constantly, a lot of the time I just remember being leant out of the car throwing up.’*

Each participant experienced these thoughts and flashbacks as distressing, though they also stated that it was the resultant thoughts that they triggered which were hard to manage.

*P6: ‘...it...brings back up obviously bad memories...’*

Several participants found it hard to discuss their intrusive thoughts, with P7 only feeling able to state:

*P7: '...brings 'bout unhappy memories...'*

Participants felt their intrusive thoughts and flashbacks were uncontrollable and could occur even when there were no obvious stimuli. This negatively impacted on them on a day-to-day basis.

*P6: '...that can randomly pop into my head at any point...just kind of randomly came out the blue...'*

All participants discussed having intrusive thoughts about their future. These tended to revolve around a fear of having another stroke.

*P2: 'Well, I'm frightened it happens again, I'm terrified and I think that it's the one thing, being frightened of it happening again.'*

*P7: 'I just hope it never happens again.'*

There was a sense that future strokes were uncontrollable, and that participants were powerless to prevent this.

*P4: '....and you know it could happen time and again, and...it's just horrible.'*

Other future-orientated intrusive thoughts revolved around adapting to their acquired disabilities, but also worrying how they would maintain any level of independence.

*P3: 'I can't do it myself. I don't like that at all. No independence at all...'*

Participants were also concerned about accessing future services.

*P5: 'What happens when you leave here and things? What's the format, the treatment?'*

It is possible that future-orientated fears are indicative of a health anxiety alongside PTSD as they are not specifically about the triggering trauma (stroke).

Participants also discussed intrusive thoughts in relation to shifts in their identity. These will be discussed in the following super-ordinate theme.

**1.2: The impact of avoidance.** Participants discussed how their wish to avoid things which reminded them of the stroke impacted on their lives. Some participants were explicit in their experiences of avoidance, stating things like:

*P7: 'I don't want be reminded 'bout it.'*

*P3: 'I try to avoid the hospital as much as I can really.'*

Others talked about wanting to avoid thinking or talking about things which reminded them of their stroke.

*P8: '...I don't really want to talk about it now. Talking about it depresses me.'*

P5 did not report any avoidance, though he stated he was doing fewer activities than he had done before his stroke. It is possible that this led to him being rated as 'avoidant' on the screening tool. However, it appears that he was not avoiding activities, but was physically unable to do things he once did due to his acquired disability.

Due to their avoidance, some participants employed safety behaviours to cope with their experiences.

*P2: 'I start thinking about this and I think in future if I go to the ballet I'll ask for an end seat.'*

When people tried to use alternative coping strategies such as distraction and trying to think about other things, these were not always found to be effective.

*P7: 'Well...I try to think about other things, (sighs)...'*

There was also a sense that even when participants could engage with their stroke on an intellectual level, that they did not engage with it on an emotional level. For instance P9 stated she did not mind talking or thinking about the stroke, and did not avoid things which reminded her of it. What she wanted to avoid was how she had become since the stroke and the shifts that she had noticed both emotionally and physically. She became tearful when this difference was raised.

*P9: 'Well, if somebody asked me about myself...I find that very difficult to cope with, and I'll cry...'*

P9 stated that prior to the stroke she had used avoidance and distraction as coping strategies for managing difficult emotions. However, due to the stroke she had lost her natural coping strategies.

*P9: '...before, if I was sad or cross, I would do something. And in the doing, I would forget it. But now I can't do it, can I?'*

This led to a sense of frustration, but also a shift in her identity as someone who 'did' to someone who 'depended'. This experience was shared with other participants, and will be explored in the 'loss' theme.

**1.3: Changed emotions.** Participants experienced changes in their emotions, either experiencing them as heightened or numbed. One participant described what sounded like anhedonia as boredom, as he was unable to gain any interest from previously enjoyed activities.

*P5: 'I get more easily bored at things....It's just...it just slows your interest very quickly.'*

Participants frequently discussed feeling angry at their situation and the events that had led to this, but also frustration at their inability to do, or concentrate on things that they had previously enjoyed.

*P3: 'I have horrible feelings when I think about it...Rage and helplessness and fear.'*

*P4: '...I got confused...and that is where it bristles me, to take all that time...because I think that kind of lets you down...you know can't do as much.'*

Participants expressed an overall sense of sadness, and a strong anxiety that they would have another stroke.

*P3: 'It's hard for me. It was a really horrible experience.'*

*P8: 'I don't want it to happen again. It is in my mind, I will admit.'*

Participants also described fear around being alone, or needing to do things alone. This was often in relation to the fear that they may have another stroke.

*P1: '....if I had a stroke I'm, I'm alone here.'*

The participants reported feeling disabled by their emotional experiences, with their challenging emotions often contributing to their difficulties in undertaking activities they had previously enjoyed.

*P2: '...and suddenly panic sets in, how the hell do I go down to breakfast so this, it started worrying me...it's turned out from a relaxing two days of being pampered...it's turned now into a what if, what happens, how am I going to come down to breakfast...'*

P2 stated prior to her stroke she had been a confident and independent woman, and she found this emotional shift very hard to manage.

Participants found that they could get suddenly tearful, or react to situations in a way that was confusing to them. Participants also reported becoming emotional thinking about the losses they had encountered, including needing to be dependent on others.

*P9: 'I could start crying at the drop of the hat since the stroke.'*

*P9: '... I have to ask for everything.....you know, that makes me angry, and it makes me sad as well.'*

**1.4: Life as uncontrollable and hopeless.** Many participants felt they were now helpless and could not control things, whereas prior to their stroke they had felt that they had control over their lives.

*P4: '....oh god. I'm not in control of things at all.'*

Shifts in emotions exacerbated participants' feeling that life was uncontrollable.

*P9: I used not to cry very much at all, but I don't have any control over my feelings these days...'*

This sense of having lost control over their emotions contributed to their overall sense of being disabled not only by their stroke, but their subsequent emotional world.

Participants found feeling out of control, helpless and hopeless about their future distressing and felt that it maintained the negative experiences that they were having.

*P5: '...got to get to a certain degree of...where you don't feel hopeless...I can't do anything. As simple things like going to the toilet....'*

*P3: '...because I was helpless for six months. It's been far too long.'*

**1.5: Memories surrounding the stroke.** Some participants discussed feeling physically well before their stroke.

*P4: 'I didn't know there was anything wrong with me on the day...'*

Although one participant described experiencing a migraine the preceding evening, in the morning he felt well enough to go to work, and described his activities as 'normal'. This sense that things were 'normal' and that there were no warning signs impacted on participants' subsequent experiences, in that they did not feel prepared for the major event that occurred. Furthermore, participants did not feel able to offer explanations for why they had felt 'normal' prior to the stroke, which emphasised the sense of unfairness that they had had a stroke.

*P2: 'I cock my legs up because I used to be a dancer...I'd done this and I'd felt really fine...so imagine...from that to not being able to lift your arms...'*

Prior to being diagnosed with having had a stroke, participants often did not believe that they had had a stroke. Three participants could not believe they were having a stroke, even though the person they were with thought this was what was happening.



*P5: 'I couldn't believe what was happening. My son kept telling me I'd had a stroke, and I kept saying I hadn't.'*

Some participants found it difficult to recall what happened during their stroke, or the subsequent days. It seems disrupted memories were caused by participants losing and regaining consciousness during their stroke, or from the medication they received. Where participants had no memories of their stroke, they reported mixed reactions. Some felt accepting of this, because they had an explanation for why they had no memories, for instance being unconscious. P9 described the sensation of being unconscious in pleasant terms.

*P9: 'I think I felt quite placid, quite serene about it all...I know I preferred to be unconscious than conscious.'*

However, most participants found it disconcerting that they could not recall what had happened to them, though they did not want the memories to return.

*P4: '...if I had some memory to come back, and you don't want that happen... it's weird.'*

Participants stated they also had confused or incomplete memories of their subsequent care.

*P6: 'I got moved from [place] A&E, [place] to [place] on a Saturday I think. That bit's a bit foggy because...I was on drugs.'*

Participants gathered more information about what had happened around their stroke from family, friends and professionals. Although this allowed them to gain a better understanding of what had happened, for some participants it heightened the sense that they had lost control.

*P4: 'It's like I'm not in control of my own body, and it's really upsetting.'*

**1.6: Needing an explanation.** Participants reported wanting to know why they had had their stroke so this could be avoided in the future, and also to help them process what had happened. P8 reiterated through the interview that he did not smoke, drank little alcohol, and had ensured he exercised. There was a sense of injustice for what had happened to him.

*P8: 'I mean I don't smoke...very little drink. So, I didn't expect...anything like this to happen to me...'*

Other participants described how they thought of alternative explanations for what was happening at the time of the stroke.

*P1: 'I thought it was too cold and my hand was dead.'*

*P6: '...four or five people walked past and said, are you okay, do you need us to call an ambulance or anything...I reckon my mind was saying, no I'm okay, I've just got a migraine...'*

P6 who was 33 at the time of his stroke had been given an explanation of what had happened, but not an explanation for why he had had a stroke at a young age. Not knowing what caused the stroke contributed to participants' fear and the sense that this was something uncontrollable that could occur at any time.

*P4: 'I can't really think about, you know, how it happened, and that I want to know why it happened....you know it could happen time and again, and...it's just horrible.'*

The importance of understanding what had caused the stroke was illustrated by P9 who found when she discovered she had a congenital condition that she felt she could feel 'better' about herself.

*P9: '...it was the first thing he said, "There was absolutely nothing you could have done to change this...It could have gone off at any time..." And I felt better about myself.'*

This appears to be linked to the blame that she had been putting onto herself for having a stroke. Blame was not a word that participants used about themselves following stroke, but it did appear that participants were looking for things that they could have done to have prevented the stroke.

*P1: '...I get, er, lot of stress, afterwards I get stroke maybe I'm not living right, yeah, I started worrying.'*

## **2: Loss**

Participants described different losses they experienced including shifts in identity and loss of independence, loss of ability, loss of current and future roles, and changes in how the world was viewed.

**2.1: Identity shifts and loss of independence.** Shifts in identity were commonly experienced, and varied. Some participants noted a dramatic loss of confidence, which led them to feel dependent on others.

*P2: 'I have no confidence at all. Whereas...before, I was full of confidence...'*

Other participants were less clear about changes they had noted, but could sense there had been a change that they did not like.

*P4: 'There has been a change, and I don't like that change.'*

Loss of independence was frequently discussed and adapting to this appeared a significant barrier to participants' emotional recovery.

*P3: 'People come along and tell me to, "You should do this. You should do that." I can't...I can't bear it.'*

*P9: 'I don't like talking about how I am now. I think that's what it is. I feel very sorry for myself. I do cry a lot.'*

P3 felt she was being infantilised by professionals, friends and family. She described feeling 'fury' at this. This was because she had 'never' liked being told what to do, and found it very challenging when others did this.

*P3: 'The rest of my life, people...they followed me for my own good. It's a very depressing thought.'*

Loss of independence not only involved 'loss', but the sense that participants needed to adapt to being dependent on others. This heightened awareness of their loss of ability, but also a shift in their identity.

*P3: 'I'm still dependent on the carers for everything...When I get up, they help me get up and get dressed. I can't do it myself. I don't like that at all.'*

**2.2: Loss of ability.** Participants discussed the impact that their acquired disability had on their sense of self. There was a general fear that they would not make a further physical recovery, and fear and some confusion about what this meant to them as an individual. Participants described this experience as 'frightening' and 'depressing'.

*P4: 'I feel like...I'm always going to have something wrong with me, and...oh God. I don't know. It's frightening...'*

*P3: 'Depressing. I've been told I won't regain my previous level of functioning, so I have no idea how I'll be functioning...'*

There was also concern regarding how others would manage their acquired disability. Participants expressed fear and anxiety that they would be a burden on loved ones.

*P5: 'I just don't want to be a burden on anybody afterward. I want to be able to help myself. But obviously that, you know, isn't going to happen.'*

This sense of being a burden on others increased participants' experience of guilt, and reduced their self-esteem.

**2.3: Loss of roles.** Participants frequently discussed a loss of role that they experienced. Participants expressed difficulties in adapting to new roles, and at times found it hard to accept support, as they felt it was *their* role to help, not to be helped.

*P2: 'I just feel so lazy...people doing things for me, like she's very good  
[name]...she'll bring me like a cup of tea and it's me who does all that...'*

Participants also discussed the loss of future roles, such as future jobs. In the case of P6 the future loss was one of becoming a father.

*P6: '...if I had children I wouldn't be able to actually be a proper father or dad,  
I wouldn't be able to take them swimming or play football with them...'*

P6 was discussing these thoughts in relation to difficult emotions and low mood that he experienced. He stated that although this thought did not come to him frequently, it was powerful and caused him to become very emotional when it did.

**2.4: Changes to social self.** Participants also reported feeling socially isolated, even when they saw friends and family. This tended to stem from a sense of separation from others due to having difficulties maintaining concentration during conversations.

*P4: '...my daughter and I...and our friends, they're here. They just start talking;  
they can't understand...I can't follow them.'*

*P6: '... if I'm in a loud situation I have difficulty concentrating on people's  
conversations...I'm not excluded from the conversation but I'm a bit further  
back from it.'*

Participants experienced this as frustrating, but also as upsetting, as it illustrated another sphere where they had experienced adverse change and loss.

**2.5: Shifts in world view.** There was also a shift in how participants viewed and interacted with the world around them. For instance P2 noticed that people on public transport did not offer their seats to people who needed them more.

*P2: ‘...he’s not supposed to go in the priority seating, it’s for old and infirm people...’*

She noticed that young people could be rude and not acknowledge other people’s needs, whilst their parents did nothing to challenge this behaviour.

*P2: ‘...they couldn’t care less and their mothers don’t say anything to them...’*

These observations made her angry, and had shifted her perception of how the world was.

*P2: ‘...it’s a different world and I see that...I feel very angry about it...’*

### **3: Support**

Participants discussed the support (positive and negative) that they received from services and friends/family.

**3.1: Negative service experience.** Participants reported that they had had a negative experience of accessing services at some point during their journey. This was in relation to both statutory and voluntary services. Their negative experiences ranged from participants feeling they had been neglected by services, to not being sure how to contact services. Some participants believed if they had received hospital treatment quicker, then their acquired disabilities would have been less.

*P2: ‘...I’m blind in that eye and had she got me there quicker, who knows, maybe they could have stopped the clot going...’*

P6 was initially found by a St John’s Ambulance worker. The worker did not appreciate that he was having a stroke, and assumed that he was intoxicated whilst

driving, even though this was before 9am on a week-day morning. P6 believes if he had received treatment sooner, then he may not have obtained his level of disabilities.

*P6: ‘...I could have had obviously quicker treatment which might have helped...’*

Further participants stated services did not meet their expectations.

*P5: ‘... I mean I thought this was a rehab place. We would get intense physiotherapy and treatment...’*

P3 felt that her negative experiences whilst in hospital contributed to the difficult emotions she felt. P3 described being ‘traumatised’ by her treatment in hospital, and at times, described treatment approaching abuse.

*P3: ‘This nurse’s station has a big sign up on the wall saying, “Abuse of staff will not be tolerated, blah-blah.” I thought you should say “Abuse of patients will not be tolerated.” ’*

For some participants it was not so much that they had received poor services, it was that they felt unsure about how to contact services, and whether they could do this as and when they needed.

*P1: ‘...professionals come to me and I don’t know how to contact them before they come here...’*

P6 found that though short-term care following his stroke was adequate, that there was no provision for medium-long term care. As such he and his wife needed to ‘fight’ for longer-term service provision. This was a further source of frustration, especially as they found that some services did not meet their needs.

*P6: ‘...you then have to fight for anything you can get and even what you get half the time is absolutely pointless so you have to fight more until you find something good...’*

**3.2: Positive service experiences.** Some participants discussed positive aspects of services they had received alongside the difficulties they had faced.

*P5: 'It's been very, very good, but like I said, only let down at the physiotherapy side of things...'*

*P2: 'Once I got into hospital I think it was positive and I knew they were really terrific...'*

Participants were grateful for this support, and noted that their positive experiences tended to be around professionals giving their time, listening to their concerns, and commenting positively on their progress.

*P2: 'I was determined to get well and they were pleased with me. You know one, one nurse said I can't believe it's you...'*

**3.3: Ineffective social support.** Participants had mixed experiences of social support. It was felt overall that although friends and family tried to help, family did not always understand participants' needs, or that they were experiencing emotional difficulties and having difficulties adapting to their acquired disabilities. Other participants found that friends and family treated them differently.

*P3: 'I can't bear being interfered with and bossed around. Never had. Lots of people have done it since I've been...had the stroke.'*

Some participants found that friends and family offered reassurance which was not useful. This caused a sense of frustration and at times anger.

*P5: 'It's just...sort of, you know, "It'll be all right. It'll come back, and it only takes time." How do they know? They don't know anything.'*

Participants also felt that their friends and/or family may be struggling to understand the impact that the stroke had had on them.

*P2: '[name] still thinks I'm her mother that can do anything...'*



This led to further frustration, but also guilt at not being the same person they had been before the stroke.

**3.4: Helpful social support.** Some participants found that friends and family were a useful support.

*P1: '...people, friends, my family are very nice...'*

*P2: 'So [name]'s coming with me and [name] looks after me, bless her.'*

Whilst this support was appreciated, it was not always easy to accept or adapt to, especially when participants had been used to being independent.

Though P6 did not explicitly discuss the positive support that he received from his wife, when he spoke about his continued efforts to obtain services, he implicitly stated that this was aided by his wife, as he talked about 'we' needing to persist to get further support.

*P6: '...to continue physio and personal therapy we had to keep...persistently badger my stroke consultant into trying to get me more...'*

#### **4: Positivity**

Some participants reported positive thoughts. These took the form of hope for further physical recovery, an understanding that they had continued to recover, recognition that they could change their physical environment to be more appropriate to their needs, and a realisation that they were not to blame for their stroke. Participants stated that this positively impacted on their mental well-being.

*P8: '...I feel I'm like 300% now and I think I could do more in life...'*

*P2: '...I feel that time will heal, you know, I feel that personally and, and I have great hope when this, eventually will pass...'*

P3 commented that she had hope for her future independence due to her decision to move to a supported accommodation complex, which had inbuilt amenities. She felt that this would enhance her independence and quality of life.

*P3: '...it has a pub and a restaurant. And of course lots of activities what's going on....I'm even betting on a better quality of life.'*

P9 stated that she was still looking for signs that could have helped indicate that the stroke was going to happen, and that this was one of her intrusive thoughts. However she also stated that knowing she had a congenital condition that had caused the stroke helped her feel reassured and she had stopped blaming herself so much. Having a reason and an explanation for what had happened to her appeared to have helped her shift her thinking and emotional state from one of blame, to one of (slight) acceptance and self-compassion.

*P9: '...there was nothing I could have done. I did find that very...I don't know. Perhaps I like myself a little bit more...'*

### **Discussion**

The main aim of the study was to explore stroke survivors' experiences of PTSD following their stroke. Further aims were to explore survivors' memories of their stroke, and to consider whether their symptoms were most consistent with a diagnosis of PTSD, health anxiety, or a combination of both. Four super-ordinate themes emerged; (1) the experiences and maintaining factors, (2) loss, (3) support, and (4) positivity. Findings indicated that participants experienced a complex range of psychosocial difficulties due to their PTSD; these were also due to adapting to life after stroke. The emergent themes are consistent with findings of research exploring the lived experience of PTSD following traumatic birth (Beck, 2004a, 2004b, 2006; Nicholls & Ayers, 2007) and ICU treatment (Corrigan et al., 2007). For example, participants discussed a range of challenging

emotions including anger, depression, frustration, and anxiety and described how they had had negative experiences of services and accessing appropriate support. The current findings also revealed that several participants had difficulties in recalling their stroke and the subsequent events. This was experienced as frustrating and confusing by most. Furthermore, the findings suggest that stroke survivors may experience PTSD and health anxiety following stroke as participants reported both flashforwards and flashbacks. The findings will now be considered in terms of their contribution to current knowledge and theory, and the study's limitations and clinical implications will be discussed.

### **Participants' experiences and maintaining factors**

The uncontrollable nature of intrusive thoughts and flashbacks was hard to manage for participants. They did not know when they would have these experiences, which led to feelings of frustration, fear, and sadness, as they would suddenly be reminded of upsetting experiences. This appeared to feed into participants' belief that the world had become less understandable. Lack of control over their experiences was a key element to participants' lived experience of PTSD and was a thread that ran through each of the themes. This finding fits with previous research, as the sense that the world was no longer predictable, and therefore uncontrollable, was a commonly reported experience in literature into PTSD following medical events (Corrigan et al., 2007; Tedstone & Tarrier, 2003).

The current study revealed that even when participants appeared to be trying to process the event intellectually (e.g., by discussing it) and reported little intellectual avoidance, avoidance was still present on an emotional level. This was demonstrated by some participants' reluctance to discuss emotions associated with their situation. It may be that emotional avoidance prevented participants from being able to fully process their traumatic memories and thus led to worsening their sense of being 'trapped'. Although

this has not been noted by previous PTSD research following medical events, it has been considered with non-medical trauma. Jaycox, Foa and Morral (1998) investigated the impact of emotional avoidance on the effectiveness of interventions with PTSD following non-medical traumas. Jaycox et al. (1998) found that even if clients revisited trauma intellectually, emotional avoidance prevented full processing of the event and reduced the effectiveness of PTSD interventions.

Although some participants displayed emotional avoidance related to discussing the stroke, challenging emotions had become part of their daily lives. Heightened emotions left participants feeling unable to do things they had once done confidently. Anger was commonly experienced, with participants feeling angry at their current situation, but also at contributing factors. The range of emotions experienced (anger, sadness, anxiety, and frustration) fits with previous research into PTSD resulting from medical events (Beck, 2004a, 2004b, 2006; Corrigan et al., 2007; Nicholls & Ayers, 2007). This suggests that stroke survivors experiencing PTSD share similar experiences to survivors of traumatic birth and ICU treatment with PTSD. However, suicidal ideation has been frequently reported in previous research into PTSD following other medical events (Corrigan et al., 2007; Nicholls & Ayers, 2007). No participants in the present study expressed suicidal ideation. This may be due to lower levels of depression than found in previous research. Alternatively the clearly defined parameters of confidentiality (i.e., if the researcher believed participants wanted to harm themselves then she would need to contact their GP) may have led to participants feeling uncomfortable sharing this depth of emotion.

The emotional difficulties expressed can be viewed as self-perpetuating, as participants' mood impacted on their functioning, which led to further deterioration in their mood. It is possible that where participants tried to avoid their emotions that these

became more powerful. Research supports the concept that avoiding challenging emotions can amplify people's emotional responses in PTSD as it prevents full emotional processing (Roemer, Litz, Orsillo, & Wagner, 2001).

Further to the difficult emotions they experienced, participants frequently reported having future-orientated intrusive thoughts (FOITs). Mundy and Baum (2004) describe these as flashforwards. FOITs expressed included the loss of the future-self due to their acquired disability, being a burden on loved ones, and beliefs that participants would have another stroke and would be unable to get help. Mundy and Baum (2004) argued that flashforwards indicated that participants were experiencing GAD instead of PTSD. Yet, FOITs discussed were all associated with stroke-related anxiety, as opposed to general anxiety. As such, the reported FOITs may indicate health anxiety as opposed to GAD, as health anxiety focuses on fears associated with health (Salkovskis et al., 2002). Ehlers and Clark's (2000) model and Foa et al.'s (1999) work offers an alternative explanation for FOITs. The cognitive models of PTSD (Ehlers & Clark, 2000; Foa et al., 1999) may describe FOITs as negative cognitive appraisals as opposed to flashforwards. Negative cognitive appraisals are not counter-suggestive of a diagnosis of PTSD; indeed they have been found to contribute to its development and maintenance (Field et al., 2008; Foa et al., 1999). It is possible that flashforwards and negative cognitive appraisals are qualitatively different. Negative cognitive appraisals could be viewed as pervasive, and almost ever present, whereas flashforwards more closely resemble flashbacks, in that they are sudden and unpredictable. FOITS discussed by participants in the current study appeared to represent flashforwards in some cases, but negative cognitive appraisals in others. Future research would be useful to further explore the extent to which FOITS characterise flashforwards or negative cognitive appraisals.

FOITs also appeared to lead to the development of safety behaviours, such as careful planning around going out. Ehlers and Clark's (2000) model states that safety behaviours may contribute to the maintenance of PTSD as they prevent participants from being able to challenge the perceived threat. Subsequently the threat remains 'live'. Nicholls and Ayers (2007) conducted qualitative research into the lived experience of PTSD following childbirth. They found women often reported safety behaviours (avoiding sex to avoid pregnancy). This negatively impacted on participants' lives as it adversely affected their relationships. Although the safety behaviours discussed in this study are different, the underlying drive may be comparable, thus illustrating further similarities between the lived experience of PTSD following stroke and other medical events.

Participants in the current study also reported having disrupted memories of their stroke and/or subsequent days. All participants discussed the difficulties they had in understanding what had happened to them due to disrupted memories. A central tenet of Ehlers and Clark's (2000) model is that disrupted memories contribute to the development of PTSD. This is because they prevent participants from piecing together what happened to them, meaning that traumatic memories cannot be fully processed. Alongside disrupted memories, participants reported a desire to understand why they had had a stroke. Ehlers and Clark's (2000) model could explain this as helping to maintain PTSD because not having a satisfactory explanation would preserve the sense that threat was 'live' as the participants could not trust that they would not have another stroke. This resulted in feelings of uncontrollability, which further fed into the sense of current, ongoing threat.

## **Loss**

The theme of loss relates to the lived experience of PTSD, but also to the wider experience of adapting to life after stroke. Regarding loss of independence, loss was accompanied by a need to adapt; participants needed to shift from being independent beings, to being dependent on others. This heightened participants' awareness of their acquired disabilities, and emphasised that they were 'different' to how they had been. Loss of role impacted negatively on participants' well-being. There was a sense that participants had become 'redundant' as they could no longer do what they had previously done. This enhanced participants' sense of vulnerability, and their new dependence on others. Loss of future roles was a substantial loss for participants, as they felt left with unanswerable questions about their future. This experience of not knowing contributed to participants' experience of being trapped by their situation. These findings closely mirror those from research exploring the lived experience of PTSD following traumatic birth and ICU treatment (Beck, 2004a, 2006; Corrigan et al., 2007; Nicholls & Ayers, 2007). This again illustrates the commonalities that people with PTSD following stroke have with other survivors of traumatic medical events with PTSD.

The theme of loss may be linked to negative cognitive appraisals of the world and themselves (Foa et al., 1999). However, it is also possible that participants were discussing wider issues of surviving stroke and adapting to life following this. It was difficult to disentangle which experiences were caused by PTSD, and which were caused by difficulties adapting to life after stroke. One possibility is that adapting to stroke fed into people's intrusive thoughts and negative cognitions, subsequently contributing to their PTSD experience. Another possibility is that participants experience loss following stroke which is independent of PTSD, or health anxiety. As such, grief models may be useful to help understand participants' experiences of loss. There are several grief models, for instance Kübler-Ross' (1969, 2005) five-stage model involving; denial, anger,

bargaining, depression, and acceptance. The model states the grief process is not linear, and people may deteriorate as well as progress. Participants' experiences mirror the stages discussed in the grief models, with participants frequently discussing denial and/or shock, anger, frustration and sadness at the losses they had experienced, and a sense that the world was no longer safe and made less sense. As such, it is possible that whilst Ehlers and Clarks' (2000) model explains the specific experiences of PTSD, grief models explain the wider experience of adapting to life following stroke.

### **Lack of support**

Participants frequently described feeling let down and neglected by services. There was a sense that this worsened their trauma experience, with some participants stating they believed their treatment had contributed to their current emotional difficulties. Participants reported poor communication from services at the time of the stroke, and during their time in hospital. This contributed to their sense that they were unsafe, and made participants feel vulnerable. Participants also reported not knowing how to contact services if they needed them, which increased their sense of reduced control. P6 (whose stroke had occurred 3 years earlier) discussed having to 'fight' for services in the medium and long-term. This led to a sense of being let down, but also raised questions about whether services could be trusted. Receiving poor treatment from services, and believing that this contributed to the development of PTSD has been commonly reported in qualitative research exploring PTSD following other medical events (Beck, 2004a, 2004b, 2006; Corrigan et al., 2007; Nicholls & Ayers, 2007). Ehlers and Clark's (2000) model would suggest that feeling unsupported and let down by professionals would contribute to participants' perceived threat, as they felt unable to trust professionals who were meant to help them.



Participants also discussed social support. Although some experienced friends and family as supportive, others found that support was not useful as it was inappropriate and poorly informed. Other participants reported that their loved ones had difficulties accepting the differences in them. This led to feelings of guilt, as participants felt they had somehow let loved ones down. Previous studies into PTSD have found that ineffective social support helps maintain PTSD, as it reduces people's opportunities to share their experiences, and thus increases difficulties in processing the event (Andrews, Brewin, & Rose, 2003; Holvea, Tarrier, & Wells, 2001; Ozbay et al., 2007). Cognitive models of PTSD (Ehlers & Clark, 2000; Foa et al., 1999) would explain the current finding by linking participants' guilt to a negative cognitive appraisal, and by linking a lack of useful support to maintaining the sense of threat, as people participants had hoped to rely upon could not provide appropriate support.

### **Positive thoughts and future hope**

A few participants discussed hope they held for the future. Regaining some independence either through regaining physical ability or altering their environment to allow more independence appeared to be what led to future hope for three participants. For another participant having an answer about why she had had a stroke allowed her to stop blaming herself to some extent, subsequently allowing her to 'like' herself more. This illustrates how important having answers can be, as they aid understanding and reduce the sense of being trapped by experiences. Nonetheless, it also demonstrates a challenge for services as it raises questions about how hope for the future can be fostered when no definitive answers can be given.

There is growing evidence for post-traumatic growth (PTG) following stroke (Gangstad, Norman & Barton, 2009). PTG is when positive psychological change occurs following exceptionally challenging life-events (Tedeschi & Calhoun, 2004). Though

participants in the current study may not have developed PTG, the positive cognitive restructuring they demonstrated in the ‘positive’ theme is an indication that PTG may be possible, as research has found positive cognitive restructuring is closely correlated with PTG (Gangstad et al., 2009). This element of positivity may also be explained by the grief models. Under the ‘acceptance’ phase, Kübler-Ross (1969, 2005) describes how thinking becomes more positive when people experiencing grief move towards recovery. Thus, the shift towards positive thinking may be indicative of slight emotional recovery.

### **PTSD following other health conditions**

To date no qualitative research has been conducted into the lived experience of PTSD following other chronic health conditions such as cancer and myocardial infarction (MI). However there are some similarities in the presentation of PTSD across different chronic health conditions. For example, research has found that participants experiencing PTSD resulting from cancer treatment and MI also report substantial emotional distress including, depression, anxiety, and anger (Doerfler, Pbert, & DeCosimo, 1994; Mundy et al., 2000). These emotions mirror those discussed in the current study. Furthermore, studies have also noted difficulties that some participants had maintaining intimate relationships following the development of PTSD due to their cancer diagnosis and treatment (Hodgkinson et al., 2007; Kornblith & Ligibel, 2003). Difficulties maintaining relationships was also found in the present study. These similarities suggest that there may be some shared experiences between stroke and other chronic health conditions, and demonstrate the need for qualitative research into the lived experience of PTSD following other medical traumas.

### **Limitations**

The present research had a number of limitations. First, the PDS was used to assess PTSD following stroke rather than a clinical diagnostic interview. This is

problematic, as for a number of reasons, the PDS is likely to over-estimate the prevalence of PTSD following stroke. For example, the PDS assesses difficulties recalling the event as part of avoidance. Stroke can cause people to lose consciousness, thus the difficulties participants reported when trying to remember important aspects of the stroke may relate to an organic event rather than PTSD avoidance. Similarly, when assessing avoidance the PDS asks participants about reductions in activities they once enjoyed. People affected by stroke may have acquired disabilities, meaning they are *unable* to do previously enjoyed activities, rather than *avoiding doing* them. The PDS does not allow for this distinction. Further difficulties include questions surrounding hyper-arousal. The PDS asks participants to rate their concentration, as difficulties concentrating can be caused by hyper-arousal. However, in stroke there may be a neurological explanation for the reduction in concentration (The Stroke Association, 2012). A diagnostic interview used alongside the PDS could have helped indicate whether there was a psychological or neurological basis to participants' responses on the PDS.

Second, it should be noted that there are proposed changes to the diagnostic criteria of PTSD in the DSM-V (American Psychiatric Association, 2013). Proposed changes include removing Criterion A (that symptoms develop following exposure to an extreme traumatic event involving actual/threatened death or serious injury, or a threat to self-integrity to self or others, alongside feelings of intense fear, helplessness or horror), ensuring that Criterion B focuses on flashbacks and nightmares as opposed to all intrusive thoughts, and that Criteria C (symptoms of avoidance) and D (symptoms of hyper-arousal) are made more specific. Changes to Criteria B-D are suggested to reduce the overlap with other conditions, such as anxiety and depression (Brewin, Lanius, Novac, Schnyder, & Galea, 2009; Forbes et al., 2011). These changes may have an impact on the current findings, as under the

DSM-V (American Psychiatric Association, 2013) some participants may not be diagnosable with PTSD. This is a limitation of using diagnostic tools (and indeed diagnoses as a means to consider people's experiences), as they are context and time specific.

Third, the current study does not explore the experiences of people who have memory problems or aphasia following stroke. This is problematic, as these people may have needs that have not yet been researched.

### **Clinical implications**

Firstly, due to the difficulties disentangling whether FOITs are flashforwards (indicative of health anxiety) or negative cognitive appraisals (indicative of PTSD), it is important that clinicians use clinical diagnostic interviews alongside diagnostic tools to ensure an accurate assessment of service users' psychological well-being. It is important to clarify diagnosis, as although the National Institute for Health and Clinical Excellence (NICE) recommends CBT for health anxiety and PTSD (NICE, 2005, 2007), the treatment protocols differ. CBT for PTSD requires service users to revisit the traumatic event to assist processing traumatic memories (Yehuda, 2002), whereas health anxiety treatment requires service users to move away from the anxiety triggering stimuli (Barsky & Ahern, 2004).

Second, the findings suggest that participants have a need to make sense of what has happened to them. It is therefore important that clinicians allow time to discuss what their stroke means to stroke survivors alongside providing information regarding prevention of future stroke. Thirdly, it may be useful to consider undertaking grief-work with stroke survivors, as the losses they have experienced can trigger a grieving response. Psycho-education may be useful for service users and their significant others regarding

what grief responses are, so they can develop an awareness and understanding as to why they are having certain emotional experiences.

A fourth implication is the need for clinicians to ensure that service users engage both intellectually and emotionally when revisiting traumatic events. Not engaging emotionally with interventions can hinder psychological recovery as it prevents service users from fully processing their experiences (Jaycox et al., 1998; Roemer et al., 2001). Ensuring effective psychological treatment is important as there is growing evidence that impaired psychological well-being negatively impacts on physical recovery following stroke (Lewis et al., 2001; Morris et al., 1992; Wilz, 2007).

### **Future research**

First, further research is needed into the experience of adaptation following stroke, as this was a substantial element of what participants' discussed. Second, due to the possibility that FOITs could be negative cognitive appraisals (indicating PTSD) or flashforwards (indicating health anxiety) there is a need for focused research into participants' FOITs following stroke. This research would need to concentrate on the content and expression of FOITs, examining whether they were pervasive and usually present (representing negative cognitive appraisals) or occur suddenly without warning (representing flashforwards). Third, findings indicate that stroke sequelae (i.e., service user's treatment whilst trying to access hospital and their subsequent treatment) had a strong emotional impact on participants. Research could explore these experiences, and then consider whether early interventions could help reduce the development of PTSD following stroke.

### **Conclusion**

The study illustrates that people experiencing PTSD following stroke have a complex range of psychosocial difficulties. On a day-to-day basis stroke survivors with

PTSD experienced challenging emotions, including anger, depression, anxiety, and a pervasive sense of frustration. Feeling that life was no longer controllable or understandable were common experiences, particularly as participants felt they did not have answers for why they had had a stroke. Not knowing was difficult to manage, and contributed to an ongoing sense of threat. The findings also indicated that stroke survivors may develop co-morbid PTSD and health anxiety, although further research is needed in this area. Ehlers and Clarks' (2000) cognitive model of PTSD offers a useful framework to consider participants' experiences of PTSD in stroke. The loss discussed indicates that although PTSD negatively impacted on participants' lives, the wider experience of adapting to life after stroke was also challenging. The study noted difficulties in disentangling whether participants' experiences were due to their PTSD or the wider experience of adapting to life following stroke. Thus grief models (Kübler-Ross, 1969, 2005) may offer a useful context to understanding participants' overall response to adapting to life following stroke alongside Ehlers and Clark's (2000) model to understand their experiences of PTSD. Clinical implications include the need for careful assessment of psychological difficulties following stroke to ensure appropriate interventions to promote psychological well-being, and thus enhance physical recovery.

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## **Section 3**

### **Appendices**

#### **Part 1 Literature Review**

Appendix 1 – Quality appraisal tool

Appendix 2 – Examples of study appraisals

Appendix 3 – Common metaphors used across papers

Appendix 4 – Example of first and second-order constructs

Appendix 5 – Translation of second-order constructs

#### **Part 2 Empirical Report**

Appendix 6 – Ethics and Research and Development approval letters

Appendix 7 – Interview schedule

Appendix 8 – Information present in screening study

Appendix 9 – Information sheet

Appendix 10 – Cover letter

Appendix 11 – PTSD diagnostic scale

Appendix 12 – Consent form

Appendix 13 – Example of data analysis

Appendix 14 – Example of participant's emergent themes and participant's comments

Appendix 15 – Synthesis of participants' emergent themes

Appendix 16 – Extracts from the researcher's reflexive journal

Appendix 17 - Peer audit protocol

## Appendix 1: Quality appraisal tool

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Table 1a  
*Quality assessment tool*

Stages	Essential criteria	Specific prompts	Criteria met?		
Scope and purpose	Clear statement of, and rationale for, research question/aims/ purposes	<ul style="list-style-type: none"> <li>▪ Clarity of focus demonstrated</li> <li>▪ Explicit purpose given, such as descriptive/explanatory intent, theory building, hypothesis testing</li> <li>▪ Link between research and existing knowledge demonstrated</li> </ul>	Yes	No	Unsure
	Study thoroughly contextualised by existing literature	<ul style="list-style-type: none"> <li>▪ Evidence of systematic approach to literature review, location of literature to contextualise the</li> </ul>	Comments:		
Design			Rating:		
	Method/design apparent, and consistent with research intent	<ul style="list-style-type: none"> <li>▪ Rationale given for use of qualitative design</li> <li>▪ Discussion of epistemological/ontological grounding</li> <li>▪ Rationale explored for specific qualitative method (e.g. ethnography, grounded theory, phenomenology)</li> <li>▪ Discussion of why particular method chosen is most appropriate/sensitive/relevant for research question/aims</li> <li>▪ Setting appropriate</li> </ul>	Yes	No	Unsure
	Data collection strategy apparent and appropriate	<ul style="list-style-type: none"> <li>▪ Were data collection methods appropriate for type of data required and for specific qualitative method?</li> <li>▪ Were they likely to capture the complexity/diversity of experience and illuminate context in sufficient detail?</li> <li>▪ Was triangulation of data sources used if appropriate?</li> </ul>	Comments:		
			Rating:		

Sampling strategy	Sample and sampling method appropriate	<ul style="list-style-type: none"> <li>▪ Selection criteria detailed, and description of how sampling was undertaken</li> <li>▪ Justification for sampling strategy given</li> <li>▪ Thickness of description likely to be achieved from sampling</li> <li>▪ Any disparity between planned and actual sample explained.</li> </ul>	Yes	No	Unsure	Comments:
Analysis	Analytic approach appropriate	<ul style="list-style-type: none"> <li>▪ Approach made explicit (e.g. Thematic distillation, constant comparative method, grounded theory)</li> <li>▪ Was it appropriate for the qualitative method chosen?</li> <li>▪ Was data managed by software package or by hand and why?</li> <li>▪ Discussion of how coding systems/conceptual frameworks evolved</li> <li>▪ How was context of data retained during analysis</li> <li>▪ Evidence that the subjective meanings of participants were portrayed</li> <li>▪ Evidence of more than one researcher involved in stages if appropriate to epistemological/theoretical stance</li> <li>▪ Did research participants have any involvement in analysis (e.g. member checking)</li> <li>▪ Evidence provided that data reached saturation or discussion/rationale if it did not</li> <li>▪ Evidence that deviant data was sought, or discussion/ rationale if it was not</li> </ul>	Rating: Yes	No	Unsure	Comments:
			Rating:			



	Context described and taken account of in interpretation	<ul style="list-style-type: none"> <li>▪ Description of social/physical and interpersonal contexts of data collection</li> <li>▪ Evidence that researcher spent time 'dwelling with the data', interrogating it for competing/alternative explanations of phenomena.</li> </ul>	Yes	No	Unsure
	Clear audit trail given	<ul style="list-style-type: none"> <li>▪ Sufficient discussion of research processes such that others can follow 'decision trail'</li> </ul>			
	Data used to support interpretation	<ul style="list-style-type: none"> <li>▪ Extensive use of field notes entries/verbatim interview quotes in discussion of findings</li> <li>▪ Clear exposition of how interpretation led to conclusions.</li> <li>▪</li> </ul>			
			Comments:		
			Rating:		
Reflexivity	Researcher reflexivity demonstrated	<ul style="list-style-type: none"> <li>▪ Discussion of relationship between researcher and participants during fieldwork</li> <li>▪ Demonstration of researcher's influence on stages of research process</li> <li>▪ Evidence of self-awareness/insight</li> <li>▪ Documentation of effects of the research on researcher</li> <li>▪ Evidence of how problems/complications met were dealt with</li> </ul>	Yes	No	Unsure
			Comments:		
			Rating:		
Ethical dimensions	Demonstration of sensitivity to ethical concerns	<ul style="list-style-type: none"> <li>▪ Ethical committee approval granted</li> <li>▪ Clear commitment to integrity, honesty, transparency, equality and mutual respect in relationships with participants</li> <li>▪ Evidence of fair dealing with all research participants</li> <li>▪ Recording of dilemmas met and how resolved in relation to ethical issues</li> <li>▪ Documentation of how autonomy, consent, confidentiality, anonymity were managed</li> </ul>	Yes	No	Unsure
			Comments:		
			Rating:		

Relevance and transferability	Relevance and transferability evident		Yes	No	Unsure
	<ul style="list-style-type: none"> <li>▪ Sufficient evidence for typicality specificity to be assessed</li> <li>▪ Analysis interwoven with existing theories and other relevant explanatory literature</li> <li>▪ drawn from similar settings and studies</li> <li>▪ Discussion of how explanatory propositions/emergent theory may fit other contexts</li> <li>▪ Limitations/weaknesses of study clearly outlined</li> <li>▪ Clearly resonates with other knowledge and experience</li> <li>▪ Results/conclusions obviously supported by evidence Interpretation plausible and 'makes sense'</li> <li>▪ Provides new insights and increases understanding</li> <li>▪ Significance for current policy and practice outlined</li> <li>▪ Assessment of value/empowerment for participants</li> <li>▪ Outlines further directions for investigation</li> <li>▪ Comment on whether aims/purposes of research were achieved.</li> </ul>				
					Comments:
					Rating:

## Appendix 2: Examples of study appraisals

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Table 2a  
*Quality assessment*

Study	Quality assessment
Allen (1998)	<p>Scope and purpose: Clear</p> <p>Design: Clearly stated and data collection appropriate</p> <p>Sampling strategy: Via health visitors at the infants' eight month follow-up from a single hospital, all women attending this appointment in an eight week window were invited to participate – appropriate.</p> <p>Analysis: Grounded theory – appropriate for study. Multiple coders.</p> <p>Interpretation: Detailed description of how interpretations decided – clear audit</p> <p>Reflexivity: None noted</p> <p>Ethical dimensions: Appropriate</p> <p>Relevance and transferability: Placed in theoretical context and clinical implications appropriately discussed.</p> <p>Overall quality: Good as clearly conducted, with clear audit. Poor as only six of the 20 women interviewed had diagnosable PTSD and the interviews are analysed together instead of separately – different themes may have emerged from the different groups. The measure used was the 1979 version of IES (out-dated). Also lack of reflexivity. Overall rating: Unsure</p>
Ayers et al. (2006)	<p>Scope and purpose: Clear</p> <p>Design: Clearly stated and data collection appropriate</p> <p>Sampling strategy: Via a voluntary sector support service, adverts, and word of mouth. Used to gain a broad range of participants.</p> <p>Analysis: Inductive thematic analysis, appropriate for study. Multiple coders</p> <p>Interpretation: Appropriate, clear audit and potentially replicable.</p> <p>Reflexivity: No evidence given</p> <p>Ethical dimensions: Appropriate</p> <p>Relevance and transferability: Placed in theoretical context and clinical implications appropriately discussed.</p> <p>Overall quality: Overall sound, though all women retrospectively completed the PDS (adapted version) for the first year after childbirth. This is a problem as the range of time since their birth ranged from 18 years to 7 months. This is likely to impact on an individual's ability to accurately recall their experiences. Overall rating: SAT</p>

### Appendix 3: Common metaphors used across papers

Table 3a  
*Common phrases and metaphors used across studies*

Author	Lack of control and helplessness	Poor, confusing or unclear memory of the event	Lack of professional care	Feeling dehumanised	Experiences of PTSD symptoms	Emotional turmoil	Impact on relationships
Allen (1998)	Feeling invisible and out of control Pain from contractions, feeling out of control		To be treated humanely Requested staff to help with the pain through pain relief but distress was maintained when it was not given	Pain from contractions Medical interventions and internal examinations Women perceived the pain as indicating that their own life was being threatened	Feeling trapped, the reoccurring nightmares of my childbirth experience.  Avoidant behaviour, intrusive imagery, self-blame, inability to cope. A rollercoaster of emotions	Anger tearfulness, panic and guilt, panic and feeling distressed.	Detached and overprotective of child Disrupted relationships
Ayers et al. (2006)				Viewed self as mutilated following the birth	Avoidant of their baby, rejecting and blaming it.	Avoiding sexual relations Depression, anxiety, anger, physically drained, suicidal	Over protective of their child Strained relationship with their partner.
Ayers (2007)	Out of control, frightened	Not remembering parts of the birth Forgetting how bad it was. Distorted perception of time.	Felt like they were not given choices	'my fear was being in this vortex of pain and screaming in agony' Fear of being torn apart by the birth.	Intrusive memories, flashbacks, dissociating from the birth	Panicky, angry, annoyed aggressive, annoyed irritable	

Beck (2004a)	<p>'I strongly believe my PTSD was caused by feelings of powerlessness and loss of control of what people did to my body.'</p> <p>Overall sense of powerlessness and feeling out of control</p>		<p>Lack of care/ understanding from professionals</p> <p>Feeling like their infant was cared for at their expense</p> <p>Not feeling believed</p> <p>Professionals not communicating with them.</p>	<p>Comparing their experience to being raped.</p> <p>Loss of dignity.</p> <p>Inadequate pain relief, prolonged, painful labour</p>	<p>Ongoing, uncontrollable flashbacks, hyper-arousal/ anxiety</p>	<p>Frightened, panicked, anxiety, depression</p>	<p>Isolate themselves from other mothers</p>
Beck (2004b)		<p>Dissociation during and after labour</p> <p>'I felt my head was floating way above my body. I struggled to bring it back onto my shoulders'</p>	<p>Poor understanding of their needs from professionals.</p> <p>Professionals not communicating with them.</p> <p>Staff experienced as arrogant and uncaring.</p>	<p>Physical pain</p>	<p>Avoidant of sexual contact.</p> <p>Avoiding their baby</p> <p>Fear of future pregnancy</p>	<p>Panic attacks, anger, depression, anxiety.</p>	<p>Lack of understanding from friends</p> <p>Fear of sexual contact due to fear of future pregnancy</p> <p>Feeling distant/isolated from their baby</p> <p>'Not only does PTSD isolate me from the outside world; it isolates me even from those I love.'</p>

Beck (2006a)	Feeling out of control, over medicated and restrained when they wanted to be able to move around in labour.			Comparing their experience to being raped 'the rape day'	Wanting to avoid their child's birthday. Finding it difficult to sleep before their child's birthday because of flashbacks, nightmares and intrusive thoughts.	Anger, anxiety, depression	'his birthday sits as a permanent barrier both in my relationship with my husband and in my sense of attachment to my child.'
Nicholls and Ayers (2007)	Feeling out of control	Dissociation '...I don't know what happened, I have no memory of what happened next.'	Lack of choice/ lack of involvement in decision-making. Poor communication from staff, feeling like continuity of care was poor.	Restricted movement/ physical restraint	Not wanting to become pregnant again so avoiding sex. Anxious Vivid memories Flashbacks	Intrusive thoughts  Anxious, confusion, feelings of violation, humiliation, dehumanization and anger	Negative impact on relationship with partner – around support they could offer. Negatively impacting on attachment with child – long term

## Appendix 4: Example of first and second-order constructs

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Table 4a  
*Examples of first and second-order constructs*

Author	First order constructs	Second order constructs	Notes and interpretations
Allen (1998)	<p>I always used to be patient, but now I fly off the handle. I just need to get rid of the frustration, but the next day I think 'God, I was so unreasonable' and then I'd feel bad and that it has put even more of a strain on my relationship with [husband].</p> <p>I want to get back at the professionals. I get an image of what a womb would look like being cut. I am left now with this anger bubbling around, you know, a mistrust of people and I am scared that my body will not heal and scared of having a coil fitted. I am not able to endure any pressure or stress now. If I really have to deal with anything I try to be cold and shut off.</p> <p>I just thought I was going to die. The pain was coming from the roots of my hair, I could feel it keep coming . . . eventually it was horrific and there was nothing I could do.</p> <p>and then I'd feel bad and that it has put even more of a strain on my relationship with [husband].</p> <p>I wanted him to be big and strong, manly if you like. The fact that he wasn't happy, it made me more scared. If I could have thought 'he's calm', it would have calmed me. [talking about husband during the birth].</p> <p>I thought 'God, if I had not had this baby I would not be going through this now' I try to distance myself, I don't really want to know.</p>	<p>Effects to self</p> <p>Relationship with partner</p> <p>Relationship with infant</p>	<p>'Effects on self' covers a large area – including how thoughts and feelings were influenced. Frequent discussion of loss of control and feeling unable to control current situation as well as traumatic birth – <b>control</b> alongside <b>emotions</b> seems central; frustration, anger. Pain was also central to the negative experience</p> <p>Perception of how husband was during birth had a further impact on their subsequent relationship – feeling let down, not supported. Also guilt at feeling behaviour to husband due to ongoing difficulties following birth</p> <p>Mixed reactions – either over protection or avoidant. Both could lead to difficulties with attachment. Emotions and PTSD experience negatively impacting on the mother-child bond.</p>

Table 5a  
Translation of second-order constructs

Overarching category	Second order constructs	Summary of meaning of second order constructs	Papers containing second order constructs
<b>Group1: Factors contributing to PTSD</b>			
Lack of Support	To communication with me: Why was this neglected? To care for me: Was that too much to ask? To provide safe care: You betrayed my trust and I felt powerless. Seeking to have questions answered and wanting to talk, talk, talk. Lack of choice or lack of involvement in decision-making	Professionals did not offer the appropriate support, which led to feelings that they were not important. Participants felt that this was why they had been left with PTSD	1, 3, 4, 5, 6
Loss of control	Perceived lack of control The end justifies the means: At whose expense? At what price? Mental defeat – felt could not go on, had no control	Participants felt that their needs had been neglected and that they had not been consulted about their care. This led to feelings of being out of control and helpless	1, 3, 5, 6, 7
Assault on integrity	Physical effects of birth Postnatal cognitive processing retrospective appraisal of birth, kept thinking back to how they felt Effects to self Pain Emotions during birth Wanting labour to end – compared to being assaulted	Rape and being physically assaulted were common metaphors used to say how participants had been left feeling by their experience	1,2, 3, 4, 5, 6, 7
Disrupted memories	Not remembering parts of the birth Poor understanding of what was going on Birth factors	Some participants found that they had poor memories, of had dissociated during the event. This led to further feelings of having lost control and hindered the ability to process traumatic memories	3, 4, 7



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**Group 2: the lived experience**


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PTSD symptoms	<p>Going to the movies: Please don't make me go.</p> <p>Future pregnancy</p> <p>A need to escape</p> <p>Fear of childbirth and sexual dysfunction</p> <p>Isolation from the world of motherhood: Dreams shattered.</p> <p>The prologue: An agonising time</p> <p>The actual day: A celebration of the birthday or a torment of the anniversary</p>	Uncontrollable flashbacks and nightmares were described, as was ways that participants tried to avoid stimuli that reminded them of their experience, often leading to difficulties in day-to-day life. Participants employed safety behaviours, including no sex to avoid pregnancy	1, 2,3, 4, 5, 6, 7
Emotional turmoil	<p>A shadow of myself: Too numb to try and change.</p> <p>Changes in mood and behaviour</p> <p>The dangerous trio of anger, anxiety and depression: Spiralling downward</p> <p>The epilogue: A fragile time</p> <p>Negative emotions in labour</p> <p>Continuity of care</p>	Anger, depression, anxiety and panic were discussed by all participants, and how disabled they had been left by these experiences.	1, 2,3, 4, 5, 6, 7
Continued lack of control	<p>Mental coping strategies – often maladaptive, and avoidant – increasing negative emotional experience</p> <p>Expectations not being met – losing control because of this</p>	Participants continued to experience a reduced sense of control. This led to a shift in their world-view, from somewhere that was fundamentally knowable and unsafe.	1, 3, 5, 6, 7
Impact on relationships	<p>Relationship with partner</p> <p>Relationship with infant</p> <p>Relationship with others</p> <p>Social interaction and trust</p> <p>Interactions with others affected</p> <p>Communication within the relationship,</p> <p>Receiving or giving support from partner,</p> <p>Coping together as a couple</p> <p>Perceptions of the child and parent-baby bond</p> <p>Strain on relationship</p> <p>Differences in attachment</p> <p>Early feelings about the child</p> <p>Later feelings about the child</p> <p>Subsequent anniversaries: For better or worse.</p>	Relationships with partners, family and children, and friends had been ruined by the experiences. Participants avoided social situations, and experienced poor attachment with their children.	1, 2, 4, 5, 6, 7,
Future fears	<p>Future pregnancy</p> <p>Subsequent anniversaries: For better or worse.</p> <p>Fear of childbirth and sexual dysfunction</p> <p>Seeking to have questions answered and wanting to talk, talk, talk</p>		1, 4, 5, 6, 7

**National Research Ethics Service****East Yorkshire & North Lincolnshire REC**

Yorkshire and the Humber Research Ethics Office  
First Floor  
Millside  
Mill Pond Lane  
Leeds  
LS6 4RA

Telephone: 0113 3050127

28 March 2011

Mrs Elizabeth P. Roberts  
Trainee Clinical Psychologist  
Sheffield Health and Social Care  
Clinical Psychology Unit  
University of Sheffield  
Western Bank, Sheffield  
S10 1BQ

Dear Mrs Roberts

**Study title:** A qualitative investigation into people's experience of trauma following stroke  
**REC reference:** 11/YH/0071

The Research Ethics Committee reviewed the above application at the meeting held on 23 March 2011. Thank you for attending to discuss the study.

**Ethical opinion**

You explained that you regard the ethical issues relate to you going into people's homes and discussing information they may find distressing. To counteract this you intend to make it clear that the interviews can be suspended if necessary, participants may bring a friend or carer with them and the interviews will take place at a venue of their choice. You will follow lone worker policy to ensure your own safety. A second coder will assess anonymised data to ensure accuracy.

The Committee pointed out that the need to audio tape interviews should be included in the information sheet and consent taken.

Members queried whether access to medical records will be required; you confirmed that you will not need access; this has transferred over from the previous study.

The Committee informed you that the number and length of time of the interviews should be included in the participant information sheet; you confirmed that you hope all participants will take part in the second interview.

Members queried whether any quotes would be used; you confirmed that you have not fully decided but if they are used they will be anonymised. The need to take consent was pointed out.

Clarification was sought on how disclosure of a safeguarding issue would be dealt with; you confirmed that if any risks are identified you will have a duty to pass them on.

This Research Ethics Committee is an advisory committee to the Yorkshire and The Humber Strategic Health Authority  
The National Research Ethics Service (NRES) represents the NRES Directorate within  
the National Patient Safety Agency and Research Ethics Committees in England

You were asked how you would deal with participants who become distressed during the interview; you explained that you would allow them to talk if they prefer but would offer time out for them to compose themselves. If necessary you would contact a person of their choice, either friend or professional, to assist them. Members queried whether the GP would be notified; you confirmed this would be the participants' choice; it would be a breach of confidentiality for you to make that decision.

The Committee raised its concerns regarding the conducting of interviews in a community building; you explained that a private room would be used.

You confirmed that all data would be stored securely at the University.

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

### **Ethical review of research sites**

#### **NHS Sites**

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

#### **Conditions of the favourable opinion**

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

*Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.*

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

*For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.*

*Sponsors are not required to notify the Committee of approvals from host organisations*

1. The participant information sheet should state that 2 interviews will be conducted that last approximately an hour. It should also say that interviews will be audio taped and anonymised quotes may be used.
2. The consent form should have sections to consent to the audio taping of interviews and use of anonymised quotes.

3. The consent form should include the following standard clause 'I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from [company name], from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.' You may remove 'medical notes' if this is not relevant to your study.
4. The correct REC name should be put on the supporting documents..

**It is responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

**You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Confirmation should also be provided to host organisations together with relevant documentation**

#### **Approved documents**

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Protocol	3	24 January 2011
Participant Information Sheet	3	24 January 2011
Interview Schedules/Topic Guides	3	24 January 2011
Research contract		
Referees or other scientific critique report		07 February 2010
REC application		01 March 2011
CV for Paul Norman		
Information presented in Safeena Ghufan's Information Sheet		
Information presented in Safeena Ghufan's 3 month follow up questionnaire		
Cover sheet/return slip	3	24 January 2011
Investigator CV		
Participant Consent Form	3	24 January 2011

#### **Membership of the Committee**

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

#### **Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

#### **After ethical review**

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National

Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email [referencegroup@nres.npsa.nhs.uk](mailto:referencegroup@nres.npsa.nhs.uk).

**11/YH/0071**

**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely



**Dr David Horton**  
Chair

Email: [nicola.mallender-ward@nhs.net](mailto:nicola.mallender-ward@nhs.net)

*Enclosures: List of names and professions of members who were present at the meeting and those who submitted written comments*

*"After ethical review – guidance for researchers"*

*Copy to: Dr Gillian McVey, Sheffield Teaching Hospitals NHS Trust  
Dr Paul Norman, University of Sheffield*



## National Research Ethics Service

### NRES Committee Yorkshire & The Humber - Humber Bridge

Yorkshire and the Humber Research Ethics Office  
First Floor  
Millside  
Mill Pond Lane  
Leeds  
LS6 4RA

Telephone: 0113 3050127

14 April 2011

Mrs Elizabeth P. Roberts  
Trainee Clinical Psychologist  
Sheffield Health and Social Care  
Clinical Psychology Unit  
University of Sheffield  
Western Bank, Sheffield  
S10 1BQ

Dear Mrs Roberts

**Full title of study:** A qualitative investigation into people's experience of trauma following stroke  
**REC reference number:** 11/YH/0071

Thank you for your letter of 31 March 2011. I can confirm the REC has received the documents listed below as evidence of compliance with the approval conditions detailed in our letter dated 23 March 2011. Please note these documents are for information only and have not been reviewed by the committee.

#### Documents received

The documents received were as follows:

Document	Version	Date
Protocol	4	31 March 2011
Participant Information Sheet	4	31 March 2011
Participant Consent Form	4	31 March 2011

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

11/YH/0071

Please quote this number on all correspondence

Yours sincerely

**Mrs Nicola Mallender-Ward**  
Committee Co-ordinator

This Research Ethics Committee is an advisory committee to the Yorkshire and The Humber Strategic Health Authority  
The National Research Ethics Service (NRES) represents the NRES Directorate within  
the National Patient Safety Agency and Research Ethics Committees in England

Ref: STH16039/GM

Sheffield Teaching Hospitals 

NHS Foundation Trust

STH Research Department  
 Royal Hallamshire Hospital  
 1<sup>st</sup> Floor  
 11 Broomfield Road  
 Sheffield  
 S10 2SE

Tel: 0114 226 5935  
 Fax: 0114 226 5937  
<http://www.sth-research.group.shef.ac.uk>

26 July 2011

Mrs E P Roberts  
 Trainee Clinical Psychologist  
 Sheffield Health & Social Care  
 Clinical Psychology Unit  
 University of Sheffield  
 Western Bank, Sheffield  
 S10 1BQ

Dear Mrs Roberts

**Authorisation of Project**

STH ref: STH16039  
 Study title: A qualitative investigation into people's experience of trauma following stroke

Chief Investigator: Mrs E P Roberts, University of Sheffield (student)  
 Principal Investigator (Local Contact): Dr Hazel Reynders, STH  
 Sponsor: Sheffield Teaching Hospitals NHS Foundation Trust  
 Funder: University of Sheffield

The Research Department has received the required documentation for the study as listed below:

- |  |   |
|--|---|
| 1. Sponsorship IMP studies (non-commercial)        | N/A   |
| Sponsorship responsibilities between institutions  | N/A   |
| Responsibilities of investigators                  | N/A   |
| Monitoring Arrangements                            | N/A   |
| 2. STH registration document: completed and signed | STH Finance Form signed by Dr Reynders, 31/3/2011 |
| 3. Evidence of favourable scientific review        | University of Sheffield, 7/2/2010                 |
| 4. Protocol – final version                        | Version 4, acknowledged by REC 14/4/2011          |
| 5. Participant Information sheet – final version   | Version 4, acknowledged by REC 14/4/2011          |
| 6. Consent form – final version                    | Version 4, acknowledged by REC 14/4/2011          |
| 7. Signed letters of indemnity                     | University and NHS Indemnity arrangements apply   |



Chairman: David Stone OBE • Chief Executive: Andrew Cash OBE

Ref: STH16039/GM

- |  |  |
|--|--|
| <b>8. ARSAC / IRMER certificate</b>                              | N/A  |
| <b>9. Evidence of hosting approval from STH directorate</b>      | Prof G Venables, Clinical Director,<br>signed STH Directorate Approval<br>Form received 13/4/2011<br><br>A Lowe, Directorate Accountant,<br>signed Directorate Approval Form<br>7/4/2011 |
| <b>10. Evidence of approval from STH Data Protection Officer</b> | N/A  |
| <b>11. Letter of approval from REC</b>                           | East Yorkshire & North Lincolnshire<br>REC, REC Ref 11/YH/0071,<br>28/3/2011 (original approval)<br><br>Letter dated 14/4/2011<br>acknowledging updated<br>documents, version 4          |
| <b>12. Proof of locality approval</b>                            | STH Research Department  |
| <b>13. Clinical Trial Authorisation from MHRA</b>                | N/A  |
| <b>14. Honorary Contract</b>                                     | N/A  |
| <b>15. Associated documents<br/>Interview Schedule</b>           | Version 3 approved by REC<br>28/3/2011   |
| <b>16. Signed financial agreement/contract</b>                   | A Lowe, Directorate Accountant,<br>signed Directorate Approval Form<br>7/4/2011<br><br>B Zinober signed STH Finance<br>Form 4/4/2011   |

The project has been reviewed by the Research Department and authorised by the Director of R&D on behalf of STH NHS Foundation Trust to begin.

Yours sincerely

  
**Professor S Heller**  
 Director of R&D, Sheffield Teaching Hospitals NHS Foundation Trust  
 Telephone +44 (0) 114 2265934  
 Fax +44 (0) 114 2265937

cc. Dr Hazel Reynders, STH





## National Research Ethics Service

### NRES Committee Yorkshire & The Humber - Humber Bridge

Yorkshire and the Humber Research Ethics Office  
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Tel: 0113 3050127  
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10 November 2011

Mrs Elizabeth P. Roberts  
Trainee Clinical Psychologist  
Sheffield Health and Social Care  
Clinical Psychology Unit  
University of Sheffield  
Western Bank, Sheffield  
S10 1BQ

Dear Mrs Roberts

Study title: A qualitative investigation into people's experience of trauma following stroke  
REC reference: 11/YH/0071  
Amendment number: AM01  
Amendment date: 31 October 2011

The above amendment was reviewed on 09 November 2011 by the Sub-Committee in correspondence.

#### Ethical opinion

The Sub-Committee reviewed the above amendment that proposes to make alterations to the timing of the post stroke follow-up due to service changes.

The Committee were satisfied with the need for the 3 month follow-up to change to a 6 week follow-up in line with service provision.

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

#### Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Information for previous study (recruitment)	5	26 October 2011
Protocol	4	26 October 2011
Protocol	5	26 October 2011

This Research Ethics Committee is an advisory committee to the Yorkshire and The Humber Strategic Health Authority  
The National Research Ethics Service (NRES) represents the NRES Directorate within  
the National Patient Safety Agency and Research Ethics Committees in England

Notice of Substantial Amendment (non-CTIMPs)	31 October 2011
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#### Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

#### R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

#### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

11/YH/0071:	Please quote this number on all correspondence
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Yours sincerely



**Dr Lynn Cawkwell**  
Vice Chair

E-mail: nicola.mallender-ward@nhs.net

*Enclosures: List of names and professions of members who took part in the review*

*Copy to: Dr. Gillian McVey, Sheffield Teaching Hospital (STH) NHS Foundation Trust*

Ref: STH 16039/JKL

Sheffield Teaching Hospitals 

16<sup>th</sup> December 2011

NHS Foundation Trust

Mrs E P Roberts  
Trainee Clinical Psychologist  
Sheffield Health and Social Care  
Clinical Psychology Unit  
University of Sheffield  
Western Bank  
Sheffield, S10 1BQ

Dear Mrs Roberts

### Protocol Amendment

STH ref: STH16039

Study title: A qualitative investigation into people's experience of trauma following stroke

Chief Investigator: Mrs E P Roberts, University of Sheffield  
Principal Investigator: (Local Contact) Dr Hazel Reynders, STH  
Sponsor: Sheffield Teaching Hospitals NHS Foundation Trust  
Funder: University of Sheffield

Amendment ref: Substantial Amendment AM01

The Investigators submitted the following documents for the above study:

- Protocol version 5, dated 26<sup>th</sup> October 2011
- Information for previous study (recruitment), version 5 dated 26<sup>th</sup> October 2011.

The REC approved the Amendment.

These have been reviewed by the Research Department, who have no objection to the amendment.

Yours sincerely

  
B? Professor S Heller  
Director of R&D, Sheffield Teaching Hospitals NHS Foundation Trust  
Telephone +44 (0) 114 22 65934  
Fax +44 (0) 114 22 65937



Chairman: David Stone OBE • Chief Executive: Andrew Cash OBE

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## Health Research Authority

### NRES Committee Yorkshire & The Humber - Humber Bridge

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17 July 2012

Mrs Elizabeth P. Roberts  
Trainee Clinical Psychologist  
Sheffield Health and Social Care  
Clinical Psychology Unit  
University of Sheffield  
Western Bank, Sheffield  
S10 1BQ

Dear Mrs Roberts

**Study title:** A qualitative investigation into people's experience of trauma following stroke  
**REC reference:** 11/YH/0071  
**Amendment number:** Amendment 2; June 2012  
**Amendment date:**

The above amendment was reviewed by the Sub-Committee in correspondence.

#### Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

#### Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Screening tool and agreement to discuss the study further "tick-box"	1	26 October 2011
Protocol	6	26 October 2011
Notice of Substantial Amendment (non-CTIMPs)	Amendment 2; June 2012	
Covering Letter		28 June 2012
Participant Consent Form	6	

## **Interview Schedule**

### **Participant Information**

- How old are you?
- How would you describe your ethnicity?
- What's your marital status?
- What's the highest level of education you achieved?
- What's your employment status?
- Is this your first stroke?
- If not, how many strokes have you had?
- How long is it since your most recent stroke?

### **1) Please tell me about your (most recent) stroke - what can you remember?**

Prompts:

- What happened?
- Tell me how you felt at the time of your stroke
- Tell me your thoughts and feelings at this time
- What can you/can't you remember?
- What are your thoughts and feelings when you think about your stroke?

### **2) How complete do you feel your memory of your stroke is?**

Prompts:

- Is there anything relatives/friends/professionals have told you happened which you didn't remember?
- Do you feel there are gaps in your memory of your stroke?
- Is there anything surrounding your stroke that you only have a vague memory of?

### **3) Do you have any problems when trying to remember your stroke?**

Prompt:

- Do you feel there are reasons for this? E.g. emotional difficulties, what was happening at the time, being unconscious.

### **4) Please tell me about any memories, worrying thoughts and/or images that suddenly pop into your head (related to your stroke)**

Prompts:

- Tell me your thoughts and feelings when these happen
- Tell me why you think you have them – if needed give further prompts of e.g. time, place, people etc
- Are these concerns about the stroke, about future events, or both?

**5) Please tell me about times when you've felt like avoiding somewhere/something/someone associated with your stroke.**

Prompts:

- Tell me your thoughts and feelings at this time
- Tell me why you think you felt this way

**6) Please tell me about times when you've felt emotionally numb, or like you were watching situations instead of being involved with them**

Prompts:

- Tell me your thoughts and feelings at this time
- Tell me why you think you felt this way

**7) Please tell me about times that you've had difficulties relaxing**

Prompts:

- Tell me your thoughts and feelings at this time
- Tell me why you think you felt this way

**8) Please tell me about any other experiences you've had**

Prompts:

- Tell me your thoughts and feelings at this time

Tell me why you think you felt this way

After this study we may wish to contact you for some further research. This will involve an interview with another researcher (Liz Roberts) who will ask you about your experiences, memories and feelings following your stroke.

If you are willing to be contacted about taking part in a further interview study, please tick here

☐

If you do not want to be contacted, please tick here

☐



Department Of Psychology.  
Clinical Psychology Unit.

Doctor of Clinical Psychology (DClin Psy) Programme  
Clinical supervision training and NHS research training & consultancy.

**Information sheet for project: *A qualitative investigation into people's experience of trauma following stroke***

You are being invited to take part in a research project. Before you decide if you want to take part it's important you understand what it involves. Please read the following information.

**Information**

This study is being undertaken by a trainee clinical psychologist from the University of Sheffield. The researcher's name is Liz Roberts and she is interested in talking to you about your experiences following your stroke. Liz's project is specifically looking at people's experiences, memories and feelings following stroke.

***Project's purpose***

It is well known that people experience a wide range of difficulties following a stroke, including physical, cognitive (thinking, memory, concentration etc.) and emotional difficulties. Some people also get recurrent thoughts, images and worrying memories which suddenly pop into their heads. Liz is hoping to explore these as a way of developing a better understanding of what's happening. It is hoped that information gathered will help professionals working with people who've had a stroke.

***Taking part: What it involves and what will happen if I choose not to take part***

If you choose to take part you'll be asked to sign a consent form. It's important that you know you can withdraw **at any time**. This is even if an interview has started, or if you have finished an interview. If you choose to withdraw this will not affect services you are receiving. Liz will not ask you why you are withdrawing and will respect your decision.



Liz has some questions she will ask you. However, she is interested in your viewpoint, and experiences, so may ask you to expand on your answers. Nonetheless, what you share is your choice and if you do not want to answer a question, just say so. Interviews will take approximately an hour. If you find it difficult to remain focused or become uncomfortable, breaks can be arranged. Interviews can take place at your home, your GP surgery, or if you prefer an alternative setting. Liz would like to take audio recordings during the interviews. This is so she has an accurate recording of everything that's been said. To make sure Liz has accurately understood what you have told her in the interview she would also like to visit you again after the interview. Liz will bring a transcript of the interview with her. This is your chance to check what was recorded and that it reflects your experiences, thoughts and feelings. This will last about half an hour.

With your consent, Liz would also like to know about the location and type of your stroke. If you give your permission to share this information, she can access this from the project you took part in associated with your memory and stroke.

### ***Potential risks of taking part***

Sometimes discussing your stroke may be distressing. If you get upset Liz will ask if you wish to proceed. If you choose not to she will see if you would like further support e.g. a friend, family member or worker contacting. If you choose to proceed Liz will allow time so you feel ok before continuing. If Liz becomes concerned about your well-being, she may advise you to contact your GP or other care workers.

### ***Potential benefits of taking part***

Whilst there are no immediate benefits for you participating in the project, some people find it helpful to talk about their experiences. Also, it is hoped the study's results will help professionals (e.g. occupational therapists, physiotherapists, nurses, psychologists, speech and language therapists) work with people who've had strokes, which may help other people affected by stroke.

### ***Confidentiality***

Information you share with Liz will be kept confidential – she will not discuss your personal details with anyone else. Furthermore, you will not be identifiable in any

publications. However, if Liz has real concerns about your well-being, she may need to let someone know. She will discuss this further with you should you choose to take part.

### ***Complaints procedure***

If you are unhappy about something that has occurred in the research, it is important that you inform The University of Sheffield. Any complaints can be addressed to: Dr. Paul Norman at the Clinical Psychology Unit, Department of Psychology, The University of Sheffield, Western Bank, Sheffield, S10 2TN. You can also make a complaint via your local hospital. To do this please contact the Patient Advice and Liaison Service (PALS) at: 722 Prince of Wales Road, Sheffield S9 4EU, Tel: 0800 085 7539 and provide information about the project.

### ***Project findings***

Liz hopes to share the findings with professionals working with people who've had a stroke and with groups for people who've had a stroke. The findings will also be published in an academic journal and may be presented at conferences. Remember all information will be anonymous and you will not be identifiable, this includes any quotes that Liz may use to help demonstrate a point being made.

### ***Ethical approval***

This project had been approved by the East Yorkshire and North Lincolnshire Research and Ethics Committee.

### ***What next?***

If you choose to take part Liz will contact you, and give you the chance to ask any questions. Liz will ask you to complete a consent form before arranging a time to start the interview process.

**Thank you for your time reading this. If you have any questions, you can leave a telephone message with the Research Support Officer on: 0114 222 6650, and she will ask Liz to contact you. Alternatively please email Liz on [pcp09epr@sheffield.ac.uk](mailto:pcp09epr@sheffield.ac.uk)**



Department Of Psychology.  
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Doctor of Clinical Psychology (DClin Psy)  
Programme  
Clinical supervision training and NHS research  
training & consultancy.

Clinical Psychology Unit  
Dept of Psychology  
University of Sheffield  
Sheffield S10 1BQ  
Date:..

Dear .....

My name is Liz Roberts and I am a trainee clinical psychologist training at the University of Sheffield. I am writing to you because you said you might be interested in taking part in an interview study looking at your experiences, memories and feelings following your stroke.

I received your details from an early study you took part in. If you are still interested in taking part in another research study, I'd be very grateful if you could read the included information sheet, then complete the below slip and return it in the provided envelope.

Yours sincerely

Liz Roberts

Trainee clinical psychologist: The University of Sheffield

.....

I.....am interested in hearing more about this project and would like Liz Roberts to ring/write to me on/at tel.:.....It is best to call in the (delete as appropriate): morning/afternoon/evening

Address:.....

.....

.....

Date:.....Signature:.....

The following questions are about details of your stroke and medical history:

1. How long ago did you have your most recent stroke? \_\_\_\_\_
2. Have you had more than one stroke? Yes No  
If yes, how many strokes have you had? \_\_\_\_\_
3. Have you experienced any previous traumatic events? Yes No
4. Have you had previous psychiatric illness? Yes No

For the following questions about your most recent stroke, please circle Yes/No or N/A (Not Applicable)

- |    |   |     |    |     |
|----|---|-----|----|-----|
| 1. | Were you physically injured?                          | Yes | No | N/A |
| 2. | Was someone else physically injured?                  | Yes | No | N/A |
| 3. | Did you think that your life was in danger?           | Yes | No | N/A |
| 4. | Did you think that someone else's life was in danger? | Yes | No | N/A |
| 5. | Did you feel helpless?                                | Yes | No | N/A |
| 6. | Did you feel terrified?                               | Yes | No | N/A |

## PART 2

Below is a list of problems that people sometimes have after experiencing a stroke. Read each one carefully and circle the number (0-3) that best describes how often the problem has bothered you IN THE PAST MONTH. Rate each problem with respect to your stroke.

	Not at all	Once a week/ once in a while	2-4 times a week	5 or more times a week	Not applicable
Having upsetting thoughts or images about the stroke that came into your head when you didn't want them to	0	1	2	3	
Having bad dreams or nightmares about the stroke	0	1	2	3	
Reliving the stroke, acting or feeling as if it was happening again	0	1	2	3	
Feeling emotionally upset when you were reminded of the stroke (for example, scared, angry, sad, guilty, etc)	0	1	2	3	
Experiencing physical reactions when you were reminded of the stroke (for example, breaking out in a sweat, heart beating fast)	0	1	2	3	
Trying not to think about, talk about, or have feelings about the stroke	0	1	2	3	
Trying to avoid activities, people, or places that remind you of the stroke	0	1	2	3	
Not being able to remember an important part of the stroke	0	1	2	3	
Having much less interest or participating much less often in important activities	0	1	2	3	
Feeling distant or cut off from people around you	0	1	2	3	
Feeling emotionally numb (for example, being unable to cry or unable to have loving feelings)	0	1	2	3	
Feeling as if your future plans or hopes will not come true (for example, you will not have a career, marriage, children, or a long life)	0	1	2	3	
Having trouble falling or staying asleep	0	1	2	3	
Feeling irritable or having fits of anger	0	1	2	3	

Having trouble concentrating (for example, drifting in and out of conversations, losing track of a story on television, forgetting what you read)	0	1	2	3	
Being overly alert (for example, checking to see who is around you, being uncomfortable with your back to door, etc)	0	1	2	3	
Being jumpy or easily startled (for example when someone walks up behind you)	0	1	2	3	

How long have you experienced the problems that you reported above? (Circle ONE)

1. Less than 1 month
2. 1 to 3 months
3. More than 3 months
4. Not applicable

How long after the stroke did these problems begin? (Circle ONE)

1. Less than 6 months
2. 6 or more months
3. Not applicable

Indicate if the problems you rated above have interfered with any of the following areas of your life DURING THE PAST MONTH. Circle Yes/No or N/A (Not Applicable)

1. Work	Yes	No	N/A
2. Household chores and duties	Yes	No	N/A
3. Relationships with friends	Yes	No	N/A
4. Fun and leisure activities	Yes	No	N/A
5. Schoolwork	Yes	No	N/A
6. Relationship with family	Yes	No	N/A
7. Sex life	Yes	No	N/A
8. General satisfaction with life	Yes	No	N/A
9. Overall level of functioning in all areas of your life	Yes	No	N/A



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**Project title:** A qualitative investigation into people's experience of  
trauma following stroke

**Name of Researcher:** Liz Roberts

**Participant Identification Number for this project:**.....

**Please initial the box**

I confirm that I have read and understand the information sheet  
explaining the above research and I have had the opportunity to  
ask questions about the project.

☐

I understand that my participation is voluntary and that I am free  
to withdraw at any time without giving any reason and without  
there being any negative consequences.

☐

I understand that I don't have to answer any questions that I  
don't want to.

☐

I agree to my responses (including quotes) being used in the  
study and understand that these will be anonymised and kept  
strictly confidential.

☐

I give permission for members of the research team to have  
access to my anonymised responses. I understand that my name  
will not be linked with research materials and I will not be  
identified or identifiable in reports that result from the research.

☐

Emerging themes	P: Pretty much everything..woke up, got dressed, shower, dress normal, went out to my car, started driving to work..then had a vague memory of hearing a noise which sounded like me clipping a wing mirror on somebody's car which, from what the policeman later said I had. I remember needing a drink so I pulled up outside a shop and then next thing was I had my head outside the car door profusely vomiting and then about five people went past saying, are you okay, do you need us to call an ambulance, which I said no, I'm okay, because I didn't have a clue what was going on...then St John's ambulance turned up which was, should have been a blessing but it wasn't because then a policemen turned up (coughs) excuse me, and based on what St John's ambulance man told him, he was claiming I couldn't use my left arm and leg, I was blatantly on something, the policeman arrested me for driving under the influence, of being under the influence, I think it was but luckily the policeman had an ounce of intelligence about him and he called an actual ambulance, paramedics then proceeded to get me out of the car, ?? board and shoved me in the back of the ambulance, took me to A&E, after stabbing me with lots of needles and then proceeded to be in A&E for..I think I went into A&E on I think it was a Thursday, and I got moved from [place] A&E, [place] to [place] on a Saturday I think. That bit's a bit foggy because I don't overly have too much recollection of that because I was on drugs. Well the St	Line-by-line analysis	Commentary
He felt 'normal' the morning of his stroke		L 27-54: he remembers pretty much everything of the actual stroke. There's a sense that things were 'normal' the morning of his stroke – a sense that there were no real warning signs for what was about to happen - ??impact on processing of the memory. He has a slight memory of hearing something which sounded like he'd clipped a car's wing mirror, which a policeman later corroborated (L32) – having to rely on others to help him clearly recall the event - ? he can't rely on his own account of events. When he stopped to buy a drink he vomited profusely – sign something was wrong, but when people offered to get him help he didn't accept – did not realise what was happening. Indicates lack of control and impacts on processing as he doesn't have a clear account of the event. St John's ambulance	Some of his memories don't feel very processed, it seems like there's a lot of detail in here, and almost a sense of being stuck, or quite fixed.
Helplessness			
Lack of control			
Unprocessed memory- need to make sense of the event			He didn't understand what was happening to him (L 39). This may be contributing to the anger that he's experiencing, especially towards the St. Johns' ambulance. He feels they should have helped, they didn't.
Realising something is wrong			
Confused memories, especially once given medication			
Lack of control			There's different indicators that his processing of the memory may have been effected – his mixed memories and, not understanding what was happening



<p>Feeling let down by professionals / services- confusion</p> <p>Unresolved feelings- anger, disappointed</p> <p>Having to rely on others to find out what happened</p> <p>Trying to make sense of his experience</p>	<p>John's ambulance were rubbish..I could have been more use to them, I can't actually even remember they gave me a drink of water, I think that was their sole contribution to being helpful, other than getting the policeman to arrest me...</p> <p><b>R:</b> <i>So a policeman came along as well</i></p> <p><b>P:</b> Thankfully, he was just passing, he wasn't called out by anyone, he was literally passing and saw the ambulance, John's ambulance and pulled over.</p> <p><b>R:</b> <i>Right, so what did the policeman do?</i></p> <p><b>P:</b> He arrested me, well he wanted my ID to start with which I struggled to get because it was on my left hand side, I reached and got it and as I say he proceeded to arrest me, apparently he did de-arrest me at some point once the paramedics had told him, yes he's actually having, had a stroke. I only know I got de-arrested because one of my friends is a policeman and he checked it up afterwards and I, I wasn't ar-, I was arrested but de-arrested pretty much immediately but then the policeman ?? informed [name] and took her to, brought her to A&amp;E</p> <p><b>R:</b> <i>So you were taken to A&amp;E?</i></p> <p><b>P:</b> Yeah..I don't, I have intermittent recollections of A&amp;E because of the amount of painkillers and drugs I was on at the time, because I had immense pain in my right hand side of my head because at the time I had like, be-, the day before, it's probably just migraine...</p>	<p>turned up, when the policeman came, St Johns told him the interviewee must be driving under the influence, so he was arrested. There's a sense of indignation that he did not receive the help and support he needed. The police called an ambulance as he suspected he was medically unwell and he was transferred to A&amp;E. There's a sense of gratitude to the police, but still anger at St Johns. He had no control over this situation, and feels passive, in that others did stuff to him – he could not contribute to what was occurring around him</p> <p>L 54-59: Confusion over when he was moved to A&amp;E due to medication – he is passive throughout – helpless and not in control</p> <p>L 59-64: St John's ambulance were useless. He's angry and feels let down, as their only contribution beyond getting him arrested, was getting him some water</p>	<p>Though he did not verbalise it, he expressed a lot of frustration and some anger at what had happened to him (how he'd been misdiagnosed by someone who should have helped him). Unprocessed and caught up in the vagueness of the memory – doesn't make sense, so can't make sense.</p> <p><b>Lack of control</b></p> <p>He's thankful that the police stopped, possibly because it could have been even longer before he got help. There's still a sense of resentment and a general feeling of incompetence on the side of services though.</p>
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Interview 6: Table of themes		
Super-ordinate themes	Sub-themes	Description
Memories of stroke	Feelings before the stroke	How he felt in himself prior to having the stroke
	Incomplete memories following the stroke	He appears to have some confused/incomplete memories following the stroke. He attributes this to the medication he was given, but also to the bleed that he was having and the swelling in his brain.
Let down by services	Inappropriate diagnosis	The St John's ambulance attendant assumed he was intoxicated and requested that the police arrest him for driving under the influence.
	Inappropriate service provision	Feeling like there was a lack of services available in relation to the medium and long-term support needs
	Having to fight for services	Feeling they don't automatically get appropriate service provision
Emotional changes	Anger, annoyance and irritation	He experiences more anger since the stroke. However, his common feelings experiences associated with the stroke are annoyance and feeling irritated
	More emotional	He does experience low mood since the stroke and can find that he cries more. He can't always control this. He's also more easily startled
Intrusive thoughts	To stroke	These include disturbing, worrying or upsetting thoughts that come to him regarding the stroke.
	Flashbacks	One main one – he sees himself being sick outside of his car. This can come at any time, and though not always disturbing in itself, it tends to trigger other worrying thoughts.
	To future	These include upsetting thoughts about the future as opposed to his actual stroke experience.
Shift in identity	Socially	This shift refers to a shift in his social identity – how he's changed in relation to his friendship group.
	Extent of his disabilities	This is about how his identity has changed due to his acquired disabilities
	Dependency	Needing to rely on others to do things that he could once do and the adjustment difficulties this brings.
	Future roles	This is how his thoughts about himself have changed
Uncertainty		This is in regard to his thoughts about what's happened to him and having questions answered.
Lack of control and helplessness		There were times both during the stroke and in the subsequent days when he felt that he did not have control over his situation. This could lead to feelings of helplessness, which were worsened by his feelings of dependency

**Participant's overall comment when presented with the theme table:**

'It all looks spot on really. However you might need to place more emphasis on the disturbing/distressing thoughts or visions as they can just happen at any moment so can come out of the blue. They can really get me down, which is not uncommon.

### Appendix 15: Synthesis table of emerging super-ordinate themes

Table 15a

Table of emergent themes

Super-ordinate themes	Participants contributing	Sub-themes	Participants	Key evidence	Key quotes	Notes
<b>Experiences and maintaining factors</b>	All	Intrusive thoughts	9	<p><b>P1:</b> Pg 4, L 86-92, Pg 6, L 141-147, Pg 6 L 133 – 135, Pg 12, L 271-273, Pg 13, L, 297-299, Pg 14, L 330-333:L 346-347, Pg 19, L 451, Pg 20, L 472-488, Pg, 21 L 493-499</p> <p><b>P2:</b> Pg14, L 318-325, Pg15, L 327-329, L 333-335, Pg 17, L 390-391, Pg 18, L 400-401, Pg 4, L 91-93, Pg 12, L 270-271, Pg 13, L 287-289, Pg 18, L 409-410, Pg 21, L 476-478, Pg 22, L 495-497, Pg 23, L 528-529</p> <p><b>P3:</b> Pg 3, L 66-67, Pg 4, L 75, L 77-79, L 81, L 83-88, L 93-98, Pg 6 L 124, L 128-129, Pg 9 L 201-203, Pg 14, L 319, L 330</p> <p><b>P4:</b> Pg 4, L 77-79, Pg 10, L 221-223, Pg 4, L 92-96</p> <p><b>P5:</b> Pg 3, L 62-63, Pg 4, L 88, Pg 5, L 111-112, Pg 10, L 227-229.</p> <p><b>P6:</b> Pg 10 L 216-217; L 226-229, Pg 11: 239-253, Pg 10, L 213-217; 220-221, Pg 11, L 238, Pg 17: L 381-388:</p>	<p>P1: ‘...bit upset or sometimes, you know, I can’t walk properly, that’s main problem....’</p> <p>P1: ‘...especially professionals come to me and I don’t know how to contact them before they come here...’</p> <p>P2: ‘...I don’t consider myself a poor old lady but I’m thinking of some poor old woman lying on the floor and somebody’s playing God there, who is she, who is this woman...’</p> <p>P2: ‘Well, I’m frightened it happens again, I’m terrified and I think that it’s the one thing, being frightened of it happening again.’</p> <p>P3: ‘I can’t do it myself. I don’t like that at all. No independence at all, that way.’</p> <p>P4: ‘...and you know it could happen time and again, and...it’s just horrible.’</p> <p>P5: ‘Yeah, because I....What happens when you leave here and things? What’s the format, the treatment?’</p> <p>P6: ‘...constantly, a lot of the time I just remember being leant out of the car throwing up.’</p> <p>P6: ‘I don’t know, just kind of randomly came out the blue...’</p> <p>P7: ‘...brings bout unhappy memories...’</p> <p>P7: ‘I just hope it never happens</p>	<p>Interview 5 was the only person to only talk about future-orientated fears.</p> <p>All other participants discussed future fears and intrusive thoughts/flashbacks to their stroke/ subsequent care.</p>

**Experiences  
and  
maintaining  
factors  
(cont.)**

Avoidance 8

**P7:** Pg 4, L 63, Pg 10, L 199, Pg 4, L 79, Pg 5, L 82-85

**P8:** Pg 4, L 85, Pg 14, L 315-317, Pg 15, L 321

**P9:** Pg 12, L 258-262, L 264-269, Pg 13, L 274-283, L 288-289

again.'

P9: 'Sometimes I wonder if there were things, little warning signs, that I could have picked up on.'

**P1:** Pg 10, L241-244

**P2:** Pg 13, L 294-296, Pg 14, L 312, Pg 23, L 524-525, Pg 13, L 281-282, L 290-291, Pg 23, L 516-518, L 520-521

**P3:** Pg 3 L 63, L 66-67, Pg 6, L 132, L 136-138, Pg 15, L 357-358

**P4:** Pg 7, 154-156

**P6:** Pg 15, L 322-325

**P7:** Pg 4, L 76, Pg 5, L 88, L 91, L 95, L 97-98, Pg 7, L 126-127, Pg 10, L 186

**P8:** Pg 9, L 186, Pg 17, L 370-377, Pg 18, L 406-407 Pg 24, L 536-537, Pg 25, L 558-560, L 568-569, Pg 27, L 613-614, Pg 28, L 628-630, Pg 37, L 835-836, Pg 16, L 363-365, Pg 21, L 463-464

**P9:** Pg 8, L 163, Pg 14, L 312-313, Pg 14, L308 Pg 14, L 311, Pg 15, L 322-325, P 15, L 337-338, Pg 14, L 303-306.

P2: 'I'm frightened to go anywhere in case..I have a stroke.'

P2: 'I start thinking about this and I think in future if I go to the ballet I'll ask for an end seat.'

P2: '....he said he just couldn't go in the kitchen...'

P3: 'I try to avoid the hospital as much as I can really.'

P7: 'I don't want be reminded bout it.'

P7: 'Well...I try to think about other things, (sighs)...'

P8: '...I don't really want to talk about it now. Talking about it depresses me.'

P9: 'Well, if somebody asked me about myself...I find that very difficult to cope with, and I'll cry...'

P9: '.....before, if I was sad or cross, I would do something. And in the doing, I would forget it. But now I can't do it, can I?'

Participant 5 did not report any avoidance. However, in his screen he'd said he did less activities that he used to enjoy. This may not have been actual avoidance, due to his acquired disability. This illustrates a limitation with the screening tool for this participant group.

Hyper-arousal was discussed in relation to people's experience of anger, as well as a general sense of heightened awareness, which contributed to feelings of vulnerability. Concentration loss was also discussed frequently and was a cause of frustration. It should be noted that

<b>Experiences and maintaining factors (cont.)</b>	Changed emotions	6	<p><b>P1:</b> Pg 2, L 38-41, Pg 11, L 255-261</p> <p><b>P2:</b> Pg 3, L 55-57, Pg 4, L 82-86, Pg 11, 244-245, Pg 21, L 484, Pg 22, L 493, Pg 28, L 653-654, Pg 30, L 681-682, Pg 41, L 952</p> <p><b>P3:</b> Pg 4, L 90, Pg 6, L126 Pg 7, L 169, Pg 9, 214, Pg 12, L 277,</p> <p><b>P4:</b> Pg 2, L 47, Pg 5, L 111, Pg 8, L 176-177 Pg 10/11, L 242-245 Pg 12, L 261-262, L 274, L 275-277</p> <p><b>P5:</b> Pg 7, L 168, Pg 8, L 171, L 176-178, L 180, Pg 9, L201-203, L 206-207, Pg 10, L 219-221</p> <p><b>P6:</b> Pg 11: L 276-281, Pg 16: L 355-357, Pg 17: 372-379, Pg 18 L 405-406, Pg 20 L 434-437, Pg 22 L 478-480, Pg 23: L 507-508</p> <p><b>P7:</b> Pg 7, L 124, Pg 8, L 151, Pg 10, L 192</p> <p><b>P8:</b> Pg 3, L 62-64, Pg 6, L 125-130, Pg 11, L 238-239, Pg 12, L 268-269, Pg 16, L 360-363, Pg 18, L 412, Pg 19, L 413, L 431-432, Pg 22, L 494-498, Pg 24, L 532-534, L 547-548, Pg 26, L 577-582 L 591-592, Pg 30, L 678-680</p>	<p>P1: '....if I had a stroke I'm, I'm alone here.'</p> <p>P2: '...and suddenly panic sets in, how the hell do I go down to breakfast so this, it started worrying me...it's turned out from a relaxing two days of being pampered...it's turned now into a what if, what happens, how am I going to come down to breakfast...'</p> <p>P3: 'It's hard for me. It was a really horrible experience.'</p> <p>P3: 'I have horrible feelings when I think about it...Rage and helplessness and fear.'</p> <p>P4: '...I got confused, you know, and that is where it bristles me, to take all that time...because I think that kind of lets you down...you know can't do as much.'</p> <p>P5: 'I get more easily bored at things....It's just...it just slows your interest very quickly.'</p> <p>P8: 'I don't want it to happen again. It is in my mind, I will admit.'</p> <p>P9: 'I could start crying at the drop of the hat since the stroke. I used not to cry very much at all, but I don't have any control over my feelings these days...'</p> <p>P9: 'If I wanted some new carpets, I'd put the carpets down. I did things, you know. And it doesn't let me do that now; I can't do them. And I have to ask for everything I want....you know, that makes me angry, and it makes me</p>	<p>concentration loss could result from biological effects of having a stroke as opposed to being a symptom of PTSD.</p> <p>Emotional shifts were also difficult to manage for participants. Some participants had used avoidance strategies before their strokes, and their strokes meant that coping they had used – keeping busy – no longer worked due to acquired disabilities. Participants also found that they were more emotional since the stroke and that overall emotions could be uncontrollable, which made them more powerful and distressing.</p>
<b>Experiences</b>					

and maintaining factors (cont.)			<b>P9:</b> Pg 8, L 164, Pg 14, L 317-320, Pg 15, 322-325, L 329-330, L 333, Pg 16, L 357-359, P16/17, L 366-367, Pg 17, L 367, Pg 19, L 422-426	sad as well.'	
	Disrupted memories	6	<b>P2</b> Pg 1, L 21-23, L 4-6, Pg 2, L 25-28, Pg 8, L 187-189, Pg 9, L 193-194, Pg 10, L 224-225, Pg 11, L 247-248, Pg 19, L 442-445. <b>P3</b> Pg 2, L 38, L 44 <b>P4</b> Pg 1-2, L 23-25, Pg 2, L 29-32, Pg 3, L 64, Pg 4, L 74, Pg 12, L 261-262, <b>P6</b> Pg 2: L 27-28, Pg 3: L57-59: Pg 4: L 84-88: Pg 5: L 106-107: Pg 7: L 145-150: L 158-160:Pg 8: L 166-172: <b>P9</b> Pg 9, L 189-190	P2: 'I don't remember, I mean I can't remember, must have passed out.' P4: 'I can't see it and...it's weird.' P4: '...if I had some memory to come back, and you don't want that happen....' P4: 'It's like I'm not in control of my own body, and it's really upsetting.'  P9: 'I think I felt quite placid, quite seren about it all. And I preferred to be... unco P6: 'I got moved from [place] A&E, [place] to [place] on a Saturday I think. That bit's a bit foggy...I was on drugs.'	Each participant described feeling 'normal' before the stroke. This appears to have contributed to their distress as there was no warning sign that anything as catastrophic as a stroke was about to happen. Participants had mixed feelings re not remembering their stroke, and at times it appears to have contributed to them feeling 'stuck'
	Life as uncontrollable and hopeless	4	<b>P2:</b> Pg 11, 244-245 <b>P3:</b> Pg 1: L 32, Pg 6, L126, Pg 7, L 170, Pg 14, L 320 <b>P4:</b> Pg 5, L 100-101, 104-105, Pg 9, L 214, Pg 10, L 226-230 <b>P5:</b> Pg 9, L201-203, L 206-207, Pg 10, L 219-221	P3: '...because I was helpless for six months. It's been far too long.' P4: '...oh god. I'm not in control of things at all.' P5: P5: '...got to get to a certain degree of a...where you're not, where you don't feel hopeless...I can't do anything. As simple things like going to the toilet....'	Loss of control was a significant factor for participants, with the sense that the world had shifted from somewhere that was knowable and safe to somewhere that they had no control – including no control over their feelings.
	Needing an explanation	6	<b>P1:</b> Pg 1, L 14-15, Pg 2, L 40-41	P1: 'I thought it was too cold and my hand was dead.'	Participants found it

				<p><b>P3:</b> Pg 1, L 30, L 35  <b>P4:</b> Pg 11, L 249-252  <b>P5:</b> Pg 2, L 36-37, L 39  <b>P6:</b> Pg 11, L 245-247, Pg 23 L 504-505  Pg 4, L 86, L 86-90, Pg 5, L 91-99, L 100-101  <b>P9:</b> Pg 11, L 236-243</p>	<p>P5: 'I couldn't believe what was happening. My son kept telling me I'd had a stroke, and I kept saying I hadn't.'  P6: '...four or five people walked past and said, are you okay, do you need us to call an ambulance or anything...I reckon my mind was saying, no I'm okay, I've just got a migraine...'  P1: '...But I get, er, lot of stress, afterwards I get stroke maybe I'm not living right, yeah, I started worrying.'  P4: 'I can't really think about, you know, how it happened, and that I want to know why it happened....you know it could happen time and again, and...it's just horrible.'  P8: 'I mean I don't smoke...very little drink. So, I didn't expect it...anything like this to happen to me...'  P9: '...and it was the first thing he said, "There was absolutely nothing you could have done to change this...It could have gone off at any time..." And I felt better about myself.'</p>	<p>hard to comprehend that they had had a stroke and sought other reasons for their experiences. This may have been due to feeling okay before their stroke, but also due to their perceptions of themselves as 'healthy'. Not having any idea that they may have been about to have a stroke could have contributed to participants' difficulties progressing their memories. This could have been further hindered by feeling like they wanted explanations for why they had had a stroke (as well as what happened) but not being able to get this – in most cases. P9 is the exception and appears to have obtained psychological benefits from having an explanation.</p>
<b>Loss</b>	All participants	Identity shifts and loss of independence	8	<p><b>P1:</b> Pg 12, L 290-291, Pg 16, L 389-392, Pg 17, L 399-401  <b>P2:</b> Pg 4, L 94, Pg 5, L,</p>	<p>P3: 'People come along and tell me to, "You should do this. You should do that." I can't....I can't bear it.'  P3: 'The rest of my life, people...they</p>	<p>There was significant loss surrounding identity shifts. Participants appeared to have lost</p>

	<p>106-133, Pg 6, L 126-134, Pg 32, L 742-746, Pg 39-40, L 909-912</p> <p><b>P3:</b> Pg 10, L 130-131; L 134-136, Pg 10, 239-242, L 245-246, Pg 11, 247-249, L 253-254, L 267, L 269, Pg 14, L 339-340, Pg 16, L 387</p> <p><b>P4:</b> Pg 5, L 109-111, L 114-115, Pg 6 L143-144, L 147-148, Pg 9, Pg 9, L 197-199, L 209-210</p> <p><b>P5:</b> Pg 5, L 101-103, L 111-112, Pg 8-9, L 192-193, Pg 9, L 209-210, Pg 10, L 324</p> <p><b>P6:</b> Pg 16: L 349-352; L 355-362, Pg 17: 383-386</p> <p><b>P8:</b> Pg 15, L 328-330, L 342, P 19, L 432-433</p> <p>Pg 20, L 439-440, L 442-444, L 447-453</p> <p><b>P9:</b> Pg 15/16, L 342-356, Pg 16, L 345-356, Pg 18/19 L 406-413, Pg 19, L 428-430</p>	<p>followed me for my own good. It's a very depressing thought.'</p> <p>P4: 'There has been a change, and I don't like that change.'</p> <p>P8: 'I don't like talking about how I am now. I think that's what it is. I feel very sorry for myself. I do cry a lot.'</p>	<p>parts of themselves, and this was difficult to adjust to, potentially keeping participants in the that they found themselves.</p> <p>There was a sense that as well as having made loses, participants needed to adapt to acquired disabilities. This was difficult for some people, and appeared to impact on their ability to process their emotions to a full extent – possibly contributing to them becoming stuck and developing PTSD. Loss of roles was a substantial theme, which was very hard for people to manage emotionally. Participants also reported</p>
7	<p><b>P1:</b> Pg 4 L 82-92, Pg 6, L 128-130</p> <p><b>P2:</b> Pg 29, L 669-670</p> <p><b>P4:</b> Pg 12, L 261-262</p> <p><b>P6:</b> Pg 7 L 121-123</p> <p><b>P7:</b> Pg 7, L 137</p> <p><b>P8:</b> Pg 14, L 299-300</p> <p><b>P9:</b> Pg 10, L 190</p> <p>Pg 15/16, L 342-356, Pg</p>	<p>P3: 'Depressing. I've been told I won't regain my previous level of functioning, so I have no idea how I'll be functioning...'</p> <p>P4: 'I feel like I'm never going to be...I'm always going to have something wrong with me, and...oh god. I don't know. It's frightening...'</p> <p>P5: 'I just don't want to be a burden on</p>	<p>anger, sadness and frustration at their losses. This appears to have helped maintain the sense that threat was current and present instead of passed – thus contributing to PTSD.</p>



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		18, L 404	anybody afterward. I want to be able to help myself. But obviously that, you know, isn't going to happen.'
Loss of ability	7	<p><b>P1:</b> Pg 12, L 290-291, Pg 16, L 389-392</p> <p><b>P2:</b> Pg 4, L 94, Pg 5, L, 106-133, Pg 6, L 126-134, Pg 32, L 742-746, Pg 39-40, L 909-912</p> <p><b>P4:</b> Pg 5, L 109-111, L 114-115, Pg 6 L143-144, L 147-148, Pg 9, Pg 9, L 197-199, L 209-210</p> <p><b>P5:</b> Pg 5, L 101-103, L 111-112, Pg 8-9, L 192-193, Pg 9, L 209-210, Pg 10, L 324</p> <p><b>P6:</b> Pg 16: L 349-352; L 355-362</p> <p><b>P8:</b> Pg 15, L 328-330, L 342, P 19, L 432-433</p> <p>Pg 20, L 439-440, L 442-444, L 447-453</p> <p><b>P9:</b> Pg 15/16, L 342-356, Pg 16, L 345-356</p>	<p>P6: '...if I had children I wouldn't be able to actually be a proper father or dad, I wouldn't be able to take them swimming or football with them...'</p> <p>P2: 'I just feel so lazy...people doing things for me, like she's very good [name] ...she'll bring me like a cup of tea and it's me who does all that...'</p>
Loss of social self	3	<p><b>P2:</b> Pg 5, L 115-116, Pg 6, L 121-123, Pg 7, L 145-150</p> <p><b>P4:</b> Pg 5/6, L 122-124</p> <p><b>P6:</b> Pg 16: L 349-352; L 355-362</p>	<p>P4: 'I think when I'm in here, and my daughter and I...and our friends, they're here. They just start talking; they can't understand...I can't follow them.'</p> <p>P6: '... if I'm in a loud situation I have difficulty concentrating on people's conversations...I'm not excluded from the conversation but I'm a bit further back from it.'</p>

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		Loss of faith in others	2	<p><b>P2:</b> Pg 38, L 897-901, Pg 40, L 915-921, L 932-936, Pg 41, L 940-943, L 947-948</p> <p><b>P3:</b> Pg 10, 239-242, L 245-246, Pg 11, 247-249, L 253-254, L 267, L 269</p> <p>Pg 16, L 387</p>	<p>P2: '...he's not supposed to go in the priority seating, it's for old and infirm people...'</p> <p>P2: '...they couldn't care less and their mothers don't say anything to them...'</p> <p>P2: '...it's a different world and I see that...I feel very angry about it...'</p>	
<b>Support</b>	5	Negative experience of services	5	<p><b>P1:</b> Pg 6, L 128-130, Pp 7-8, L 170-175, Pg 18, L 424-428, Pg 21, L 509-510</p> <p><b>P2:</b> Pg 15, L 337-339, L 344-346, Pg 17, L 375-386, Pg 18, L 411-422, Pg 20, L 468, Pg 21, L 481-482</p> <p><b>P3:</b> Pg 4, L 75; L 77-79; L 83-88, Pg 5, 109-111, L 113-115, Pg 7 L 155-157, Pg 8, L 172-175, 185-192, L 195, Pg 17, L 404-406</p> <p>Pg 19, L 427-429.</p> <p><b>P5:</b> Pg 3, L 65-67, L 69-71, Pg 3/4, L 74-76, Pg 4, L 81-84, Pg 5, L 112-115, L 119-121, Pg 6, L 124, L 126, L128-131, L133-136, L 140-141, Pg 8, L 185-187, Pg 11, L 259-260, Pg 12, L 265-267, Pg 13, L 297, Pg 13, L 304, L 306-310, Pg 15, L 340-343.</p> <p><b>P6:</b> Pg 3: L 42-46, Pg 6: L 134-136, Pg 20: L 441-451, Pg 21: L 457-466, L 472-</p>	<p>P1: 'But the main thing is I don't know who to contact round here for help...'</p> <p>P2: '...I'm blind in that eye and had she got me there quicker, who knows, maybe they could have stopped the clot going...'</p> <p>P3: 'This nurse's station has a big sign up on the wall saying, "Abuse of staff will not be tolerated, blah-blah." I thought you should say "Abuse of patients will not be tolerated." '</p> <p>P5: '... I mean I thought this was a rehab place. We would get intense physiotherapy and treatment, and get you out of here as soon as they possibly could...'</p> <p>P6: '...if they had then I could have had obviously quicker treatment which might have helped...'</p> <p>P6: '....you then have to fight for anything you can get and even what you get half the time is absolutely pointless so you have to fight more until you find something good...'</p>	<p>Negative experiences varied greatly, with participant 1 just stating they were not sure how to access services, to others stating they felt that their experience led to their PTSD (participant 3) and that if services had been more efficient they may have received needed care earlier (participants 2 and 6).</p>

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Positive experience of services	3, though mainly P2 and 5.	<p><b>P2:</b> Pg 17, L 390-391, L396-397, P22, L 500-501, Pg 23, L 515, Pg 55, 1271-1272</p> <p><b>P5:</b> Pg 4, L 78-79, Pg 6, L 139, Pg 14, L 327-328, L 332</p> <p><b>P6:</b> Pg 22, L 494-496</p>	<p>P2: 'Once I got into hospital I think it was positive and I knew they were really terrific...'</p> <p>P2: 'I was determined to get well and they were pleased with me. You know one, one nurse said I can't believe it's you...'</p> <p>P5: 'It's been very, very good, but like I said, only let down at the physiotherapy side of things...'</p>	Participants 2 and 5 felt they received good services as well as poor services. Though limited, participant 6 stated he'd also experienced some good support from his consultant, but also from one physiotherapist.
Ineffective social support	5	<p><b>P1:</b> Pg 4, L 82-83, Pg. 5 L 101-105, Pg 12, L 275-276, Pg 14, L 330-331, Pg 16, L 371-373, Pg 21, L509-510.</p> <p><b>P2:</b> Pg 5, L 115-116, Pg 6, L 121-123, Pg 7, L 145-150</p> <p><b>P3:</b> Pg 10, 239-242, L 245-246, Pg 11, 247-249, L 253-254, L 267, L 269, Pg 16, L 387</p> <p><b>P4:</b> Pg 5/6, L 122-124</p> <p><b>P5:</b> Pg 9, L 210-212, P9/10, L 216-218</p>	<p>P2: . '[name] still thinks I'm her mother that can do anything...'</p> <p>P3: 'I can't bear being interfered with and bossed around. Never had. Lots of people have done it since I've been...had the stroke.'</p> <p>P5: 'It's just...sort of, you know, "It'll be all right. It'll come back, and it only takes time." How do they know? They don't know anything.'</p> <p>P6: '.... if I'm in a loud situation I have difficulty concentrating on people's conversations...I'm not excluded from the conversation but I'm a bit further back from it.'</p>	Participants appear to have found it difficult to explain to others their needs and the shifts that had occurred for them. This led to feelings of isolation, but also frustration.
Helpful social support	3	<p><b>P1:</b> Pg 3, L53, L 55, L57, Pg 5, L 107-109,</p> <p><b>P2:</b> Pg 5, L 99-102, Pg 6, L 139-136, Pg 32, L 737-739</p> <p><b>P6:</b> Pg 20, L 449-451, Pg 21, L 457-461</p>	<p>P1: '...people, friends, my family are very nice so, one from [place], one, the other one not far from here...'</p> <p>P2: 'So [name]'s coming with me and [name] looks after me, bless her.'</p> <p>P2: '...she's very good [name] I mean, she'll bring me like a cup of tea and it's</p>	However, some participants discussed

					me who does all that...' P6: 'We had to, to continue physio and personal therapy we had to keep, badger and persistently badger my stroke consultant into trying to get me more...'	useful support that they had received from friends/family. This was appreciated, though again they sometimes found this hard to access due to the shift in roles it illustrated. With P6 he did not explicitly discuss the support his wife gave, though when he talked about getting more services, there was a sense that they had fought together to get more services.
Positivity	4	Hope for the future	3	<b>P2:</b> Pg 52-53, L 1208-1211, Pg 53, L 1212-1215, L 1219, L 1227-1229, 1231-1232 <b>P3:</b> Pg 12, L 287, Pg 13, L 301, Pg 16, L 378, Pg 19, L 457 <b>P8:</b> Pg 14, L 312-313, Pg 15, L 336-340, Pg 36, L 814-817, L 822-825	P2: '...I feel that time will heal, you know, I feel that personally and, and I have great hope when this, eventually will pass...' P3: '...it has a pub and a restaurant. And of course lots of activities what's going on....I'm even betting on a better quality of life.' P8: '...I feel I'm like 300% now and I think I could do more in life...'	Despite all the difficulties that participants faced, some continued to hold onto hope of recovery/an improved quality of life. This did not seem to be due to having had their stroke recently, as 3 participants who still had hope had experienced their strokes over a year ago.
		Reassurance	1	<b>P9:</b> Pg 11, L 240-244	P9: '....there was nothing I could have done. I did find that very...I don't know. Perhaps I like myself a little bit more...'	

P1: I think it is interesting that he made reference to my age. I don't think of myself as young, but he referred to be as 'young' a few times. He stated that he didn't want to 'burden' me with his experiences – what does this mean, that I wouldn't be able to manage the difficulties that he's experienced, that I wouldn't be able to understand? I think this impacted on the experiences that he's shared with me. It feels almost like he gave me the edited version, and that someone else may have got a different story.

P3: I am aware that this woman is the same age as mum. I felt sad during the interview, and felt strongly that she was angry and frustrated at her loss of independence. I did think afterwards, 'Imagine if that was mum, how would she feel?'. There may be a danger that I'm thinking too much about these experiences in relation to how my mum would feel (who's also an independent woman who's still working, as this participant was till her stroke). Remain grounded in her experience!!

P6: I found this quite a difficult interview. He's young, and it struck me when he was talking about not feeling able to be a father due to not being active enough. However, I need to be aware that I am pregnant (not visibly during the interview – he did not know I am pregnant) and have a toddler. Being a parent has become a valuable role to me, and I think I would have felt a great sense of loss had I not been able to become a parent. Is this feeling of loss coming more from me?

**Protocol for peer audit of research findings**

It was agreed by the peer supervision group that each individual could send a different transcript to each member of the group to be audited.

AIMS: To audit the data analysis process i.e. check themes are warranted and grounded in the raw data

To provide a means by which 40% of each researcher's analyses are audited

The researcher will provide each peer auditor with the following:

- Aims of the research
- A non-annotated transcript
- Annotated transcript
- Table of themes (including super-ordinate, sub and examples)\*
- Any supplementary data necessary to see the link between the transcript and final themes e.g. diagrams, narrative summaries

\*It is recognised that each researcher will have their own idiosyncratic way of presenting data.

Each peer auditor will follow the steps below:

*“Engage in one thing with a reflective purpose, rather than lots of things with a corrective purpose”* Larkin (2011)

- 1) Read the non-annotated transcript once to familiarise themselves with the data. Note down initial thoughts of themes, anything that stood out.
- 2) Read the annotated transcript and table of themes once – be observant of any sections completely missed (i.e. no emergent themes noted).
- 3) Work through 10% of the transcript length (section chosen by auditor), checking the method used to obtain themes
  - Has the theme come from the data, yes or no?
  - Does a label or theme seem directly related to a theory rather than coming from the data?
  - Is the account coherent & plausible? Could anything be clearer?

- 4) Discuss thoughts from the process with the researcher especially any additional ideas on anything of interest/importance they may have missed.

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